FAMILY PLANNING FOR WOMEN WITH SEVERE MENTAL ILLNESS IN RURAL ETHIOPIA:

A QUALITATIVE STUDY

By

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DECLARATION

I, Tigist Zerihun Kebede, hereby declare that this thesis is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

Background: Family planning is a crucial issue for all women of reproductive age, but in women with severe mental illness (SMI) there may be particular challenges and concerns. As primary care-based mental health care is expanded in low- and middle-income countries (LMICs), there is an opportunity to improve family planning services for women with SMI. However, research exploring unmet family planning needs of women with SMI in such settings is scarce.

Aim: To explore the family planning experiences, unmet needs and preferences of women with SMI who reside in a predominantly rural area of Ethiopia

Methods: A qualitative study design was used. Women with SMI who were participating in the ongoing population-based cohort study in Butajira were selected purposively on the basis of responses to a quantitative survey of current family planning utilization. In-depth interviews were conducted with 16 women with SMI who were of reproductive age until theoretical saturation was achieved. Audio files were transcribed in Amharic, translated into English and analysed using a Framework Approach using Open Code qualitative data analysis software.

Results: The findings were grouped into four main themes. The first theme focused on the broader context of intimate relationships and sexual life of women with SMI. Sexual violence, assault and exploitation were reported by several respondents, underlining the vulnerability of women with SMI. Lack of control over sexual contact was associated with unwanted pregnancies. The second theme (childbearing and SMI) was around attitudes towards childbearing in women with SMI. Respondents described negative views from community members and some health professionals about the capacity of a woman with SMI to give birth and bring up a child. In most cases, it was assumed that a woman with SMI should not have a child at all. In the third theme (family planning for women with SMI), respondents spoke of their low access to information about family planning and systematic exclusion from existing services. In the fourth theme (preferred family planning services), the respondents had concerns about the ability of primary care workers to understand their specific family planning needs, but also valued proximity of the service and privacy. The importance of addressing health worker and community attitudes was emphasized.

Conclusion: This study has provided in-depth perspectives from women with SMI about the broader context of their family planning experience, needs, barriers and how integrated primary care services could better meet their needs. Empowerment of women with SMI to access information and services needs to be an important focus of future efforts to improve the reproductive experiences of this vulnerable group.

Contents

ABBREVIATIONS:

CSA: Central Statistical Agency of Ethiopia

DSS: Demographic Surveillance Site

DSM- IVTR: Diagnostic and Statistical Manual of Mental Disorders, 4^{th} edition text revision

FMOH: Federal Ministry of Health

LMICs: Low and Middle-Income Countries

PHC: Primary Health Care

SMI: Severe Mental Illness

STD: Sexually Transmitted Disease

WHO: World Health Organization

Chapter One: Introduction

Family planning is the planning by an individual or couple about the number and timing of having children. Family planning also includes the use of contraceptives. There are significant health and socioeconomic advantages when women are able to access family planning, and can exercise the right to use or not to use contraceptives (Cottingham et al., 2012; Zuehlke et al., 2012). Although family planning is an important issue for all women of reproductive age, it may be more complex and challenging for women living with severe mental illness (SMI).

First, women with SMI have increased rates of unplanned pregnancy than the general population (Dickerson et al., 2004; McLennan & Ganguli, 1999; Miller & Finnerty, 1996). A host of reasons may be associated with less effective family planning in women with SMI (McLennan & Ganguli, 1999). Medication interactions between some psychotropic medication and hormonal contraceptives may render contraception less effective (Crawford, 2002). Symptoms of mental illness, such as sexual disinhibition in mania, can directly increase the risk of unplanned pregnancy or may interfere with a woman's capacity to access or utilize family planning (Procter et al., 2013). Mental illness also increases the vulnerability of women and may undermine their ability to negotiate the use of various family planning methods (Bonugli et al., 2010; Coverdale & Turbott, 2000; Khalifeh et al., 2015b).

Second, women with SMI have increased risks of pregnancy, birth, and neonatal complications. This includes placental abnormalities, ante-partum hemorrhage, preterm labour and fetal distress, and their infants are more likely to be small for gestational age, and at higher risk of sudden infant death syndrome (Jablensky et al., 2005; Jones et al., 1998; Nicholson et al., 1998; Nilsson et al., 2008).

Some of these complications may be directly related to SMI (Meltzer-Brody, 2011; Schneid-Kofman et al., 2008). Even after adjusting for socio-economic status, women with SMI tend to have poorer health than their counterparts without SMI, due to effects of mental illness treatment and lifestyle factors such as smoking and lack of exercise (Jablensky et al., 2005; Jones et al., 1998).

Third, family planning is a crucial issue for women with SMI due to the perinatal effects of psychotropic medication. The risk of teratogenicity from some psychotropic medications is highest during the first trimester of pregnancy, with the critical period of exposure often occurring before pregnancy is detected or disclosed. Moreover, discontinuation of the medication during pregnancy increases the risk of relapse (Jablensky et al., 2005). Psychotropic medications may also cross into breast milk, which adds an important consideration in settings with high levels of exclusive breast feeding and no realistic option to bottle feed (Burt et al., 2001; Tényi et al., 2000; Viguera et al., 2007a).

For all of these reasons, family planning and education about future pregnancy is of critical importance in woman living with an SMI during childbearing years. It is recommended that information about family planning should be integrated into regular health care services (Miller & Finnerty, 1996). However, access to family planning advice and methods is low in most low-and middle-income countries (LAMICs) and is likely to be even lower in women with SMI, thereby limiting the effectiveness of this approach. For example, Nigeria, in common with the rest of sub-Saharan Africa, has low levels of family planning coverage, estimated to be 9.6% (Goliber et al., 2009). Even though family planning constitutes a central element of primary care in Nigeria, there is no family planning service targeted at women with SMI (Tunde-Ayinmode, 2013). To date very few studies have investigated the issue of family planning among women with SMI (Becker & Krumm, 2006). In a recent systematic review on family planning amongst women with SMI, the included studies were predominantly conducted in high-income countries and very little or no literature from developing countries (Tunde-Ayinmode, 2013). Unfortunately, there is limited detail available on the family planning services for women with SMI. However, this points to a large gap in the literature.

Family planning service studies in Ethiopia primarily focus on contraceptive use and attempts at increasing knowledge and positive attitudes towards modern contraceptives (Tilahun et al., 2013). The prevalence of contraceptive use for all women is 29%. Injectables are the most common type of modern contraceptive method used, followed by implants and pills used by less than 8% of modern contraceptive users (CSA, 2014). However, as yet there has been no investigation into any other family planning services in the country (CSA, 2014; Tilahun et al., 2013). At the present time, family planning service in Ethiopia is being provided at all levels

of health care providers and within community by health extension workers specifically (Kesetebirhan, 2011).

Poorer access to family planning is associated with lower education, lower socio-economic status and living in a rural area (Tekelab et al., 2015). Even though children are highly prized within Ethiopian culture, a population-based study of pregnant women in rural Butajira found that of the 1046 women interviewed, 46.1% of them reported that their pregnancy was unwanted and this pregnancy was associated with high symptoms of common mental disorders (Hanlon et al., 2009). At present, no studies have investigated access to family planning in women with SMI in Ethiopia. There is also no published evidence on how women with SMI prefer family planning services to be rendered. The plans to scale- up mental health care by integrating into primary care services in Ethiopia (FMOH, 2012) provide a potential opportunity to provide more holistic care to women with SMI and improve their access to family planning advice.

Family planning in women with SMI

In general, women with SMI have little contact with reproductive and general health providers; thus, it has been suggested that interaction with mental health care providers may present the only opportunity to address family planning needs (Pozzi et al., 2014). In an old qualitative study with 21 reproductive age women from the Massachusetts Mental Health Center in the United States, most women with SMI reported that they would like to receive family planning counselling in mental health settings (Grunebaum et al., 1971) and most mental health care professionals agreed that family planning information should be provided to patients with mental illness (Coverdale et al., 1992). Providing family planning services in conjunction with mental health services could have additional advantages for women but may not reach the majority of women with SMI in LMIC settings because of the low accessibility of specialist mental health care (Guedes et al., 2009; Moura et al., 2012; Viguera et al., 2002).

Family planning for reproductive-aged women with SMI may be provided by general health workers who have better expertise in reproductive health. Moreover, contraception planning is well-recognized as an important component of prenatal and postpartum care (Pozzi et al., 2014). A recent literature review highlighted that women with SMI who are of childbearing age should be engaged in discussions about family

planning (Seeman, 2013). Family planning education is, therefore, critical to women with SMI for a number of reasons. Family planning counselling provides an opportunity to optimize mental health care, including medication regimens, before conception and to support adherence to contraceptives which is otherwise complicated by hospitalization and frequent relapse (Guedes et al., 2009). Despite higher risk of unplanned pregnancy, birth and abortion, women with SMI are more likely to receive inadequate family planning and contraceptive services.

Research investigating the family planning needs of these vulnerable women with SMIs is scarce, particularly in low and middle-income countries, such as Ethiopia, where there are a number of barriers for people with SMI to access mental health care in the current system of centralized specialist mental health services. This has led to a very high treatment gap for people with SMI, estimated to be over 90% (Alem et al., 2009; Thornicroft, 2007). At present, there is no integrated service which seeks to address the family planning needs of women with SMI or to provide them with adequate education about prospective pregnancy. This is a concern given that unplanned pregnancy in women with SMI is not only common, but can have so many adverse effects. The new National Mental Health Strategy of Ethiopia is seeking to address the treatment gap for SMI by ensuring that mental health care becomes an integral part of primary care services across the country. This provides the opportunity for mental health care to become more holistic, specifically to address reproductive health and family planning needs of women with SMI more adequately. Even though there is a plan to scale-up mental health care, with recognition of women with SMI, as a vulnerable group, there is no evidence about how the needs of women with SMI can best be met.

Aims & Objectives

The aim of the present study is to gain a better understanding of the nature of the family planning unmet needs in women with SMI and how the barriers to accessing family planning might be overcome. The specific objectives include:

1. To investigate the family planning experiences of women living with severe mental illness and;

2. To explore the attitudes of women with severe mental illness towards family planning interventions and their unmet needs

Chapter Two: Literature Review

2.1. Introduction

The literature review in this chapter will begin by defining severe mental illness (SMI) and giving an overview of the prevalence and burden of SMI, both globally and within Ethiopia. The available evidence on the issues facing women with SMI of childbearing age and their family planning needs will then be reviewed in order to identify gaps in the evidence base.

2.2. Severe mental illness

Although there is little uniformity in how SMI is defined in practice and no operational definition (Ruggeri et al., 2000), in most instances SMIs are defined by diagnosis, level of disability and/or the presence of disorganized behavior (Schinnar et al.,1990). SMIs have been defined as comprising symptoms that may include impaired reality testing, impulsivity, disorganized thought, and difficulty in establishing and maintaining long term relationships (Greenberg et al., 2015; Kessler et al., 2001).

The term SMI includes the diagnoses of schizophrenia and psychosis, severe mood problems such as bipolar disorder and severe major depressive disorder. However, the term SMI goes beyond diagnostic criteria and requires enduring disability (Parabiaghi et al., 2006). SMIs are associated with significant impairment of functioning and quality of life over a long period of time, both for the people who are affected by SMI, and for their families and friends (Parabiaghi et al., 2006). A systematic review reported that the different approaches to the definition of severe persistent mental illness affect estimates of the prevalence of SMI (Schinnar et al., 1990).

Mental disorders are detected in all countries of the world (Kessler et al., 2009). Studies using systematic methods estimate that the lifetime prevalence of all psychotic disorders is at least 3% (Perala et al., 2007). It is reported that the 12month prevalence of SMI ranges from 4 to 6.8% in half of the countries included in the World Mental Health Survey (Kessler et al., 2009). Many mental disorders begin in adolescence or early adult hood and have significant adverse effects on subsequent role transitions in a person's life, which contributes to significant role impairment

(Kessler et al., 2009). Mental disorders are known to have a much earlier age of onset than most chronic medical conditions (Kessler et al., 2007). They also contribute a considerable amount to the global burden of disease measured using disability-adjusted life years, which combine premature mortality (years of life lost with disability (Whiteford et al., 2015). In SMIs, the greatest contribution to the burden is through their association with long term disability and dependency, although mortality is also an under-recognized consequence of SMI (Fekadu et al., 2007). Most people living with an SMI do not receive treatment for the condition, and many of those who do showed marked delay in seeking treatment (Greenberg et al., 2015; Thornicroft, 2007). The treatment gap for people living with SMI is large, particularly in LMICs (Demyttenaere et al., 2004; Kessler et al., 2001).

In this thesis, SMI is operationalised to include schizophrenia, bipolar disorder; and major depressive disorder with psychotic features. These disorders will now be described in further detail. Schizophrenia is a serious and disabling psychiatric illness (Bizzarri et al., 2009; Insel, 2010; Picchioni & Murray, 2007). Schizophrenia occurs in all populations worldwide. In a number of systematic reviews, the prevalence of schizophrenia has been found to be similar in all parts of the world (Goldner et al.,2002), ranging from 4 to 10 per 1000 people (McGrath et al., 2008; Mueser & McGurk, 2004). There does not appear to be a difference in the incidence of schizophrenia between high income countries (HIC) and LMICs (Saha et al., 2006). The burden of schizophrenia is large (Bhugra, 2005; Whiteford et al., 2013; Whiteford et al., 2015). People living with schizophrenia have two to three times increased risk of mortality when compared to the general population (McGrath et al., 2008) and psychiatric co- morbidities are also common (Buckley et al., 2009). Schizophrenia is among the top ten most disabling illnesses (Mueser & McGurk, 2004) and causes a substantial burden upon families and caregivers of people living with schizophrenia (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Chan, 2011; Igberase et al., 2012; Kebede et al., 2003; Rossler et al., 2005).

Bipolar disorder tends to be a recurrent disorder which is characterized by severe shifts in mood and marked impairment in carrying out day-to-day activities (Muller-Oerlinghausen et al., 2002; Yadav et al., 2013). Bipolar disorder is recognized to be a major public health problem worldwide (Hilty et al., 2006). It has a higher prevalence ranging from2.8 to 6.5% (Bauer & Pfennig, 2005), which is higher previously thought ranging from 1.3 to 1.6% (Grant et al., 2005; Muller-Oerlinghausen et al., 2002; Perala et al., 2007). Bipolar disorder is associated with a higher risk of suicide attempts,

psychiatric co-morbidities and poorer quality of life than the general population (Ten Have et al., 2002). The quality of health care provided to people living with bipolar disorder has been found to be worse than for people living with other chronic physical conditions or other psychiatric illnesses (Brissos et al., 2008). In studies from European countries, people with bipolar disorder were found to have an equivalent or higher level of disability and impairment when compared to people with schizophrenia or major depressive disorder (Pini et al., 2005). Bipolar disorder is associated with high psychiatric and medical co-morbidities, such as substance use disorders and diabetes mellitus, both globally and in LMICs (Esan & Esan, 2016; Fajutrao et al., 2009), and is one of the top ten causes of work disability worldwide (Hirschfeld & Vornik, 2005; Kleinman et al., 2003). This disorder places a tremendous burden not only for people living with the disorder themselves, but also upon families, society and the health care system (Dean et al., 2004).

Depression is one of the leading cause of disability globally (Mathers et al., 2008). Major depressive disorder with psychotic features is characterized by high symptom severity, chronic course, functional impairment and poor treatment response (Gaudiano et al., 2009; Souery et al., 2011). A systemic review on prevalence of Major depressive disorders found that major depressive disorder point prevalent after adjustment of methodological difference was,4.7% (4.4-5.0%) and annual incidence of 3.0% (2.4-3.8%) (Ferrari et al., 2013).

Depressive disorders are a leading contributor to the global burden of disease of which major depressive disorder contribute substantial for the disease burden globally (Kessler & Bromet, 2013; Whiteford et al., 2013). It accounted for more than 4.2% total disability adjusted life years (DALYs) in the year 2010 (Demyttenaere et al., 2004; Greenberg et al., 2015; Whiteford et al., 2013). In the WHO disease burden report, the disability associated with major depression was estimated to be fifty percent higher in women than men (Mathers et al., 2008). The economic burden of depressive disorders is increasing globally (Greenberg et al., 2015). Depression with psychotic features is associated with poor outcome and chronic course (Buoli et al., 2013). Depression is associated with co-morbid anxiety disorders and substance abuse (Lamers et al., 2011) and is an important contributor to suicide; in a systematic review of psychological autopsy studies, it was estimated that 56.7% of people who commit suicide may have had depression (Bertolote & Fleischmann, 2002; Cavanagh et al., 2003; Fleischmann et al., 2005). Even though communicable diseases continue to contribute to a large proportion of the disease burden in Africa, around ten percent of the total disease burden in sub-Saharan Africa is attributed to depression (Kessler et

al., 2007; Whiteford et al., 2013). The prevalence of depression ranges from 4.9 to 30%, depending on the tool used in sub-Saharan African countries (Abas & Broadhead, 1997; Bitew, 2014; Gureje et al., 2006; Herman et al., 2009; Westley, 1993).

Major depressive disorder with psychotic features are not rare in the general population and is also more common among women than men (Keller et al., 2007; Ohayon & Schatzberg, 2002). An old study estimated the prevalence of major depressive's disorder with psychotic features in the United States and found that 15% of major depressives reporting a lifetime history of psychosis. (Johnson et al., 1991). Another study conducted a decade later with 18,980 participants aged from 15-100 from 5 European countries (United Kingdom, Germany, Italy, Portugal, and Spain) reported a prevalence of 0.4% of major depression with psychotic feature (Ohayon & Schatzberg, 2002). Major depressive disorder with psychotic features tends to be associated with treatment challenges and poor outcomes (Rothschild, 2003). A follow up study from the US among 61 patients with major depressive disorder with psychotic features and 59 patients with major depressive disorder without psychotic feature reported almost double risk for those with psychotic features of mortality compared to patients with nonpsychotic depression (Vythilingam et al., 2003).

2.3. Severe mental illness in Ethiopia

There is a large burden among people living with SMI in African countries, including Ethiopia (Fekadu et al., 2007; Gureje et al., 2006). In Ethiopia, mental illness is the leading contributor to disability-adjusted life years amongst the non-communicable diseases (Abdulahi et al., 2001). In a rural Ethiopian setting, mental illness comprised 11% of the total burden of disease, of which schizophrenia and depression were both in the top ten most burdensome conditions (Abdulahi et al., 2001).

There have been a number epidemiological studies of people with SMI in Ethiopia. These studies have provided valuable insights into the prevalence and burden of these illnesses in the country. In a large-scale, population-based study of nearly 70,000 people in south-central Ethiopia, the prevalence of schizophrenia and bipolar disorder was very similar to that seen in high-income countries (0.5% and 0.3-0.6%, respectively) (Kebede et al., 2006; Kebede et al., 2004). Kebede and his colleagues

reported that functional outcome of schizophrenia is markedly lower than the general population (Kebede et al., 2006; Kebede et al., 2005). When followed up prospectively, one third to one half of people living with bipolar disorder were found to have an ongoing functional impairment associated with recurrent relapses of the illness (Fekadu et al., 2006). A higher number of depressive episode relapses were found in women when compared to men in this population (Fekadu et al., 2006). The families of people with bipolar disorder were found to be more burdened economically than the families of those with other types of chronic illness, such as diabetes, hypertension and asthma (Zergaw et al., 2008). In a population-based study, it was found that, even though social support and networks are strong in rural Ethiopia, schizophrenia causes a huge social and economic burden, as in high income countries (Kebede et al., 2003).

Furthermore, more than 80% of people with schizophrenia perceived stigma (Bifftu & Dachew, 2014) and it is estimated that stigma contributes to discontinuation of medication (Assefa et al., 2012). In a community, based study of 178 relatives of people with SMI, 75 % of respondents perceived that they were stigmatized because of having a relative with SMI (Shibre et al., 2001), in keeping with findings from other LMICs (Lauber & Rossler, 2007). After 10 years of follow-up of a population based sample of people with schizophrenia in Butajira, most people were found to have an unfavorable clinical course (Fekadu et al., 2015) and the standardized mortality ratio doubled when compared to general population it was 213.9 (95% confidence interval (CI) 177 to 256) (Fekadu et al., 2015). Despite all these findings of adverse illness impact, only 10% of people with SMI ever access mental health care (Kebede et al., 2003). In a follow-up study of in the same rural population, there was substantial association severe depression with increased mortality morbidity (Bitew, 2014; Fekadu et al., 2006), and low help seeking behavior (Hailemariam & Haddis, 2011).

There is little evidence about physical health care for people with severe mental illness in Ethiopia (Merga, 2015). There are two cohort studies available with available data at five and 10 years, thus studies showed a mortality rate among people with SMI to be 6-fold and 2-fold compared to the general population, respectively. This was attributed to comorbid medical illness (Fekadu et al., 2015; Teferra et al., 2011) .These findings were replicated in a study conducted at the only mental specialized hospital in Ethiopia. This study found that 10 % medical comorbidities among people with SMI (Merga, 2015).The current health care system in Ethiopia encourages an

integrated mental health care service into medical practice and is assumed to improve the physical health care access to people with mental illness (FMOH, 2012)

2.4. Search strategy for a structured review on pregnancy and family planning among women with SMI.

This structured literature review was conducted by choosing the studies based on the study aim and objectives. The aim of this review is to identify and Summarize existing evidences of family planning for women with SMI.

This aim was met via the following objectives:

1. To identify the accessible related literatures on severe mental illness among reproductive age women

2. To illuminate the effect of pregnancy on SMI

3. To illuminate the effect of SMI on pregnancy

2.4.1. Search strategy

2.4.1.1. Search method

An electronic database search of PubMed, Medline, Google scholar, Academic Search Premier, and Psych ARTICLES was conducted between July and September 2015 for published, peer-reviewed journal articles. The following search terms were used:

(1) “Family planning” AND “Schizophrenia” OR “Bipolar” OR “Major depressive disorder” AND “Pregnancy” AND “psychotropic”

(2) “Family planning” AND “women with severe mental illness “AND “experience” (3) “Mental illness “AND” Pregnancy” AND “outcome”

(4) “Psychotropic” AND “pregnancy” AND “outcome”

Inclusion criteria

(1) Studies that examined women with severe mental illness (defined below) (2) English language

(3) Without restrictions for date

Exclusion criteria

Studies reported in a language other than English and studies conducted in non-human participants.

2.4.1.2. Number of studies identified

Using the search methods specified above, 567 articles were identified across all databases. The titles of all 567 articles were assessed for relevance. Of these, 342 were found to be potentially relevant, for which the abstract was assessed for possible inclusion and 6 duplicates excluded. 336 of these abstracts were regarded as possibly relevant, for which the full manuscripts were obtained. After reviewing the 336 full manuscripts, 70 of these met the inclusion criteria and were included in the review.

In order to identify further studies, a search was then conducted for articles that were referenced in the 78 articles included in the review. This led to the identification of a further 59 articles (See Appendix A: PRISMA Flow Diagram). The titles of all 59 additional articles were assessed for relevance. Of these, 34 were found to be potentially relevant. The abstracts were assessed for possible inclusion. Four were excluded because they were not relevant, leaving 30 articles for which the full text articles were read. Of these, 25 articles were included in the study. Therefore, a total 95 studies were in this the review after the methodology and limitations were assess critically to confirm the relevance for this study. These studies cited in different subtitles of the study such as SMI, substance use and reproductive health(n=19), Sexual abuse in women with SMI(n=11), Effect of pregnancy and child bearing on SMI (37), Effect of SMI on pregnancy and neonatal out comes (13), Women with SMI and antenatal health service use (n=7), SMI and perinatal complications(n=13) and Family planning context for women(n=8).

2.5. Severe mental illness in women of reproductive age

According to the available literature, a number of challenges affect women living with an SMI who are of reproductive age. These include comorbid substance use and an increased vulnerability to sexual abuse and exploitation resulting in an increased risk of contracting a sexually transmitted disease and unwanted pregnancies. These issues will be described below in further detail.

2.5.1. SMI, substance use and reproductive health

Having a co-morbid substance related disorder and SMI significantly increases the risk of acquiring sexually transmitted diseases (Meade, 2006). Many women with SMI and a co-morbid substance problem reported that their substance use affected their ability to have protected sex during sexual encounters (Kelly et al., 2001). Moreover, the cognitive effects of SMI may inhibit motivation to cease substance use during pregnancy (Bailey et al., 2012; Haug et al., 2014; Irner, 2012; Kelly et al., 2001; Kelly et al., 2012; Pinto et al., 2010).

Women with an SMI who are of childbearing age are more likely to utilize tobacco, alcohol and other drugs than the general population (Bizzarri et al., 2009; Hartz et al., 2014). Even though any illicit drug exposure in utero is associated with poorer birth outcomes, alcohol, nicotine, cannabis and cocaine exposure have been related to more adverse offspring outcomes (Shankaran, 2007; Zammit et al., 2009). It has been found that prenatal exposure to either maternal smoking, alcohol, cocaine or cannabis use is related to poor neurobehavioral and cognitive outcomes in children, including symptoms of attention deficit hyperactivity disorder(ADHD), increased externalizing behavioral disorders, decrease in cognitive functioning, and deficits in learning and memory tasks (Hannigan et al., 2010; Huizink, 2006; Shankaran, 2007; Zammit et al., 2009). Studies have shown that smoking in women with a diagnosis of schizophrenia is independently associated with intrauterine growth restriction, preterm delivery and perinatal death because of oxygen restriction (Billert & Florek, 2010; Ellman et al., 2007; Wehby et al., 2011). Alcohol consumption during pregnancy can cause fetal alcohol syndrome and opiate use may result in premature birth and neonatal abstinence syndrome (Billert & Florek, 2010; Grant et al., 2005; Wehby et al., 2011).

2.5.2. Sexual abuse in women with SMI

Women with SMI in general, and not only those with co-morbid substance use disorders, are also vulnerable to sexual abuse (Bonugli et al., 2010). SMI increases the sexual vulnerability of women (Bonugli et al., 2010; Weinhardt et al., 1999). Research findings indicate that women with SMI are more likely to be victimized than those without SMI (Coverdale & Turbott, 2000; Lipschitz et al., 1996; Tsigebrhan et al., 2014)

Women with SMI are at greater risk of sexual coercion (Weinhardt et al., 1998) and other forms of sexual abuse (Goodman et al., 2001). In a, cross sectional descriptive study of India, which included 146 women who had been admitted to a psychiatric hospital, 30% reported sexual coercion (Chandra et al., 2003). In another study of 242 women with SMI attending community mental health centers in Rhode Island in US, 53.2% reported sexual abuse at least once in their lifetime and 43.3% reported repeated abuse (O'Hare et al., 2015).

Given that women with SMI have been found to be more vulnerable to high risk sexual behaviors and coercive sexual encounters (Weinhardt et al., 1999), it is not surprising that they are at an increased risk of contracting sexually transmitted diseases (STDs) and having an unwanted pregnancy. In a study of women with SMI found that they tend to have more lifetime sexual partners, which increase the risk of sexually transmitted infections (Dickerson et al., 2004). Women with bipolar disorder and schizophrenia have a higher risk of STDs than women with depression (Hariri et al., 2011) and are at increased risk of contracting HIV (Alem et al., 2009; Carey et al.,1997). Many women with SMI find themselves pregnant as a result of sexual coercion(Buckley, 2013; Marengo et al., 2015).

2.6. Pregnancy complications among women with SMI

Women with SMI are at increased risk of a range of pregnancy complications. First, mental disorders generally are common in the perinatal period and may affect women with SMI. The risk of relapse among women with SMI during pregnancy and the postpartum period is increased. Second, treatment with psychotropic medication complicates the issue of family planning in women with SMI. Third, women with SMI appear to under-utilize antenatal care. Finally, psychiatric illnesses are risk factors for poor obstetric outcome, such as perinatal mortality and congenital malformations.

2.6.1. Effect of pregnancy on SMI

2.6.1.1. Perinatal mental disorders

There is limited information about SMI in the perinatal period, but mental disorders in general have been found to be common (Jones et al., 2014). Estimates of the prevalence of perinatal disorders range widely (Paschetta et al., 2014). Perinatal psychiatric illness impairs functioning (O'Hara & Wisner, 2014) and has a potentially negative impact on maternal health and birth outcomes (Meltzer-Brody & Stuebe,2014). The perinatal period is associated with the highest risk of SMI, either as the continuation of a pre-existing illness or a new onset (Jones et al., 2014). The prevalence of SMI in the first 12 weeks after childbirth was found to be 1.03 per 1000 births (Munk-Olsen et al., 2006).

In a prospective community study of 1065 women in rural Ethiopia, perinatal mental disorder was associated with prolonged labour, delayed initiation of breast-feeding (Hanlon et al., 2009), increased episodes of diarrhea in the neonate (RR 2.15; 95% CI 1.39 to 3.34) (Ross et al., 2011) and functional impairment in the woman (Senturk et al., 2012). In another prospective study of 561 women from the same community, maternal depression was associated with an increase in child mortality (Risk Ratio 2.3; 95% CI, 1.0 to 4.9) (Deyessa et al., 2010).

2.6.1.2. Relapse of SMI during pregnancy and post-natal period

The risk of relapse among women with SMI during pregnancy and the postpartum period is high (Viguera et al., 2000). In an audit study of 45 women using perinatal mental health services in the USA, 26% of women with a history of psychiatric illness were admitted during their pregnancy and 38% had a relapse that required inpatient care within a year of delivery (Green et al., 2008). Doyle and colleagues conducted a retrospective study of case notes of 78 women referred to perinatal mental health services between the years 1998 and 2009, and found that 47% of women with bipolar disorder experienced a relapse in the postpartum period (Doyle et al., 2012). This is further supported by another study that found a 50% risk of perinatal relapse of bipolar disorder (Di Florio et al., 2013; Munk-Olsen et al., 2009).

In an Indian study, postpartum psychosis was found to be an important predictor of suicidal ideation and suicide attempts (found in 38% of participants) (Babu et al.,

2008) and that the onset was earlier when compared to postpartum onset mania or depression (Di Florio et al., 2013). The incidence of hospitalization during pregnancy and postpartum period was found to be 9.24% in Swedish women with a history of previous psychiatric hospitalization (Harlow et al., 2007).

2.6.2. Psychotropic medication in prenatal women with SMI

Treatment with psychotropic medication complicates the issue of family planning in women with SMI. All psychotropic medications readily cross the placenta (Newport et al., 2007; Newport et al., 2005). However, most women with SMI cannot stop taking their medication because of the risk of relapse during pregnancy and the postpartum period (Boden et al., 2012; Buchanan et al., 2010; Yatham et al., 2006). For instance, the recurrence of bipolar disorder during pregnancy and post-partum after discontinuation of the medication was found to be 2.9 times more frequent than in non-pregnant women (Viguera et al., 2000; Viguera et al., 2007b). The risk of recurrence of major depressive disorder in the perinatal period was also significantly higher, with an estimated hazard ratio of 5.0 (95% confidence interval: 2.8 to 9.1; *P*<.001) after discontinuation of medication (Cohen et al., 2006).

Because of the higher risk of unplanned pregnancy in this specific population, there is an increased risk of psychotropic medication exposure to the infant during the early months of the pregnancy (Boden et al., 2012; Einarson & Boskovic, 2009; Gentile,2010; McCauley-Elsom et al., 2010).

Infants of mothers who take antipsychotic medications during pregnancy are also at increased risk of withdrawal symptoms, including extra-pyramidal side effects such as abnormal muscle tone, tremors, motor restlessness, spasticity, difficulty with feeding, weak neonatal reflexes, jaundice and intestinal obstruction (Desai et al., 2009). Exposure to atypical antipsychotics during pregnancy has been associated with increased risk of adverse obstetric and neonatal outcomes such as metabolic complications (Cummings et al., 2011). Recent studies also suggest adverse long-term neurobehavioral abnormalities in children associated with maternal atypical antipsychotic use (Abel, 2013), such as poorer neuromotor performance than antipsychotic naïve controls (Bailey et al., 2012). Even though the evidence is limited on this issue, neither first nor second generation antipsychotics appear to be totally free of risks for neonatal complications (Gentile, 2010).

Many first line mood stabilizers used in the treatment of bipolar disorder are associated with increased risk of congenital malformations; nevertheless, discontinuing treatment during pregnancy increases the risk of bipolar mood-episode relapses (Epstein et al., 2015; Viguera et al., 2000). Antenatal lithium treatment has been associated with neonatal complications such as poor respiratory effort, cyanosis, cardiac rhythm disturbances, low APGAR score at birth, pre-term delivery, small for gestational age, lethargy, hypotonia, poor oral feeding, weak neonatal reflexes, nephrogenic diabetes insipidus and thyroid dysfunction (Newport et al., 2005; Pinelli et al., 2002). There is an increased risk of cardiovascular malformations in foetuses exposed to Lithium, specifically Ebstein's anomaly (0.05–0.1%) (Bejot et al., 2008; Doyle et al., 2012; Iqbal et al., 2001; Kozma, 2005; Pinelli et al., 2002).

Sodium valproate exposure in early pregnancy is associated with a rate of up to 20% for serious perinatal adverse outcomes, including malformations. Exposure to valproate has been associated with increased risk of neurodevelopmental abnormalities (Harden, 2008; Jentink et al., 2010). Both carbamazepine and valproate have been associated with an increased risk of neural tube defects and other adverse effects on the foetus, including intrauterine growth restriction, congenital anomalies, impaired postnatal development, and behavioural problems (Bromley et al., 2013; Cummings et al., 2011; Tomson & Battino, 2012).

Medication treatment for depression in pregnancy has also been associated with complications for the fetus. In a study analyzing data from a Swedish birth registry, preterm delivery, persistent pulmonary hypertension and neonatal complications were associated with the tricyclic antidepressant use (Reis & Kallen, 2010). Reza and colleagues found a 1.3-fold increase in congenital malformations in 2,062 women who had been exposed to selective serotonin reuptake inhibitor antidepressants during pregnancy (Berard et al., 2010).

2.6.3. Women with SMI and antenatal health service use

Studies investigating reproductive health service usage of women living with any mental illness from high income countries have consistently reported underutilization of antenatal care, in terms of timing of first ANC appointment and attending for the recommended four visits (Bennedsen et al., 1999; Cresswell et al., 2013; Hauck et al., 2013; Kelly et al., 2001; Kim et al., 2006; Sacker et al., 1996).

There is evidence that women with SMI do not access adequate antenatal care services. In a population based study amongst 607 women with schizophrenia and

1,821 control women in Taiwan, women with schizophrenia had a significantly lower average number of prenatal care visits when compared to the controls (7.92 vs. 8.72, P <0.001) (Lin et al., 2009). These findings were similar to a study investigating births in 1537 women with schizophrenia in Denmark: 7% of women with schizophrenia had less than three antenatal care visits compared with 2.7% of controls (Bennedsen et al., 2001).

2.6.4. Effect of SMI on pregnancy

SMI is a risk factor for poor obstetric outcome, including perinatal mortality and congenital malformations, with estimated odds ratios of 2.4; 95% CI, 1.5–3.7, *P* < 0.001 and OR 1.4; 95% CI, 1.01–1.9 *P* = 0.03, respectively (Schneid-Kofman et al., 2008b). In a cohort study of births, compared to controls, women with bipolar disorder were at significantly higher risk of experiencing ante-partum hemorrhage, placental abnormalities, and abnormalities related to alcohol, tobacco, and illicit-substance use. Similar findings were observed in a large scale observational study from Taiwan, where bipolar disorder was associated with a significantly higher chance of low birth weight, preterm birth, placental abruption and spontaneous abortion compared to births to women without SMI after adjusting for other infant, maternal and paternal factors (Lee & Lin, 2010). These findings from Taiwan confirmed by population based cohort studies have also shown that the infants of women with bipolar disorder have an increased risk of adverse perinatal outcomes such as low birth weight, small for gestational age and preterm delivery irrespective of treatment (Boden et al., 2012; Jablensky, 2000; Lee & Lin, 2010; Mei-Dan et al., 2015).

Higher rates of unplanned pregnancy planned pregnancy and higher rates of induced abortion were also seen in a case control study of 63 euthymic women with bipolar disorder and the same number of women without a psychiatric history, with adjustment of sociodemographic factors such as age, education and socioeconomic condition (Marengo et al., 2015). Bipolar disorder during pregnancy has also been associated with increased risk of disruptions in the support system and family functioning, and also increased maternal suicide risk (Gold & Marcus, 2008). Women with SMI were found to have an increased risk of pregnancy, birth, and neonatal complications, as well as placental abnormalities, ante-partum hemorrhage and foetal distress found in a retrospective study of 3,174 children from Australia (Jablensky; et al., 2005).

Bennedsen and colleagues also suggest an increased risk of preterm delivery, low birth weight, and small size for gestational age in children of women with schizophrenia (Bennedsen et al., 1999). Women with schizophrenia were more likely to have placental abruption, to give birth to infants in the small for gestational age, and to have children with cardiovascular congenital anomalies after considering maternal age, parity and sex of the infant (Bennedsen et al., 2001; Sacker et al., 1996). Complications other than low birth weight, such as stillbirth and neonatal death, were higher in pregnancies after the onset of illness than in pregnancies occurring before the woman became mentally ill (Howard et al., 2003; Jablensky et al., 2005). In summary, the high rates of risky sexual behaviour and vulnerability to sexual coercion and abuse among women with SMI, resulting in unplanned and unwanted pregnancies, underscores the importance of understanding their awareness and practices related to family planning (Viguera et al., 2000). Furthermore, pregnancy in women with SMI is accompanied by risk factors which are associated with poor obstetric outcome, including poor antenatal care, increased risk of relapse, co-morbid substance use, exposure to potentially teratogenic medications, malnutrition and poverty (MacCabe et al., 2007; Nilsson et al., 2008; Schneid-Kofman et al., 2008a).Given that a number of studies have determined that a significant number of women with SMI are sexually active, but not routinely using birth control (McLennan & Ganguli, 1999), an in-depth investigation into the family planning needs and services provided to women with SMI is warranted.

2.7. *Family planning context for women*

Although family planning coverage is increasing worldwide, in many LMICs the prevalence of contraceptive use is low and the unmet need for family planning services remains high (Cleland et al., 2011). Several African countries, including Mali, Chad, Sierra Leone, and South Sudan have reported less than 10% use of contraception (Alkema et al., 2013; Chae et al., 2014).

Although family planning use of all reproductive age women in Ethiopia has been increasing and is considered to be a success story, family planning is still low and associated with a number of unmet needs. According to the Ethiopian Demographic and Health Survey report, contraceptive coverage increased from 14% in 2005 to 29% in 2014 among married women. However, even though 25% of women surveyed reported that they did not want to have more children or had just had a pregnancy, they were not using any form of contraceptive (CSA, 2010).

Knowledge and practice of family planning are affected by many factors. In a study from south-western Ethiopia (Jimma Town) involving 260 women, family planning knowledge and practice was strongly influenced by sociocultural norms in which the man takes the main role in decision making because of the low social status of women (Beekle & McCabe, 2006). In a large study from Western Ethiopia (n=1003), low levels of education, rural residence and low income were associated with lower contraceptive use (Tekelab et al., 2015). In southern Ethiopia (n=1998), only 11.9% of women reported using any kind of contraceptive, with the unmet need for contraception estimated to be 37.4% (Hailemariam & Haddis, 2011). In a study from Butajira involving 5746 married women, the prevalence of contraceptive use was 25.4% (95% CI: 24.2, 26.5) and unmet need for contraception was 52.4% (Mekonnen & Worku, 2011).

Chapter Three: Study Design and Research Methodology

3.1. Study design

In the present study, a qualitative study design was used. Qualitative research methodology is used when a study is focused on the situations and the meaning of human lives and experiences. In qualitative studies, it is possible to examine underlying values, beliefs, and assumptions for the purpose of induction or theory-development and to gain an in-depth understanding about what induces the individual to behave in a particular way (Davidson et al., 2008; Lewis et al., 2015). In general, the goals of qualitative health research are to answer the questions 'what', 'how' or 'why' about the social characteristics of health, illness and health care. Qualitative research discovers "real life" experiences by collecting complete and rich data in a multi-dimensional and open research process.

This qualitative approach is often used when phenomena are unexplored or theory has not evolved yet (Creswell, 2014; Patton, 2005). Employing qualitative methodologies in research gives the chance to describe a phenomenon in the words of the participant rather than imposing a defined answer pattern. In addition to this, the flexibility of the researcher during the data collection allows for rich exploration to answer questions as to how and why something is occurring (Boyce & Neale, 2006; Mack et al., 2005; Malterud, 2001). Qualitative research may be able to uncover views, beliefs and perspectives that would have been otherwise invisible in a purely quantitative approach (Choy, 2014; Davidson et al., 2008). Such an approach has particular application when researching a topic with people who are marginalized and may not feel empowered to speak in a highly-structured interview (Griffin, 2004; Razafsha et al., 2012). Rural women who have a SMI in a low-income country may be especially reluctant to disclose information in a quantitative study format. The flexibility of the qualitative study format, the nature of the interviewer-interviewee live interaction and the assumption that the respondent is the expert are all attributes of the qualitative approach which make it applicable to the current study (Razafsha et al., 2012; Whitley & Crawford, 2005).

3.2. Study setting

The study was conducted in the Federal Democratic Republic of Ethiopia. Located within the Horn of Africa, Ethiopia is a landlocked country situated between Eritrea to the north and northeast, Djibouti and Somalia to the east, Sudan and South Sudan to the west, and Kenya to the south (see Figure 3.1).

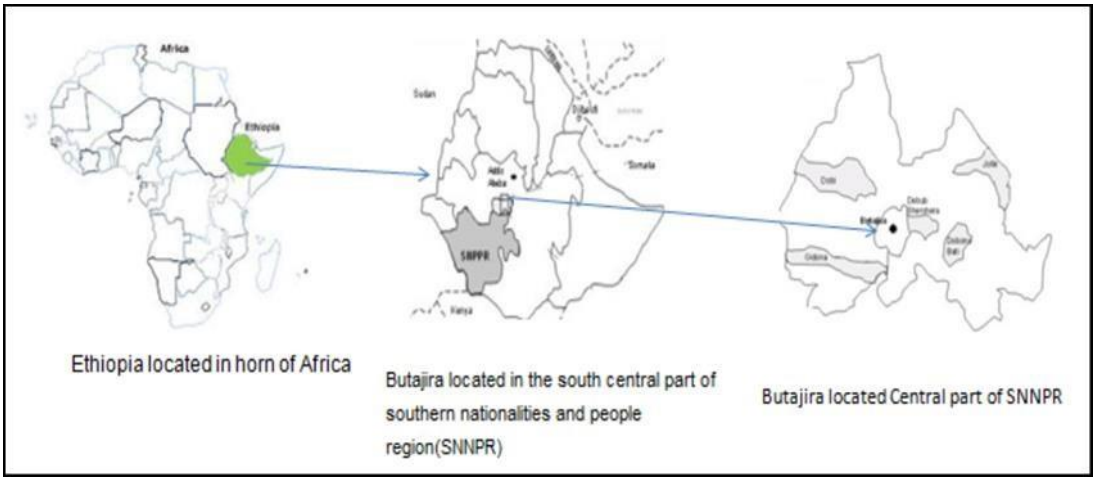

Figure 3.1 Map of study area

With a population of over 90 million, Ethiopia is the most populated non-coastal country in the world, and the second-most populated nation on the African continent (CSA, 2007). Half of the population is female (CSA, 2010). Only 16 percent of the Ethiopian population lives in urban areas (CSA, 2010). Ethiopia occupies an area of 1,100,000 square kilometers (420,000 sq. m). Addis Ababa is both the capital and the largest city of Ethiopia and the Head Quarters of the African Union, inhabited by about 3.41 million people (CSA, 2010). Ethiopia's official language is Amharic followed by English, especially for dealing with the international community, diplomacy and commerce.

This study was carried out in and around Butajira, which is a town located in the Gurage Zone of the Southern Nations, Nationalities and Peoples' Region. Geographically, Butajira lies within southern part of Ethiopia, and is a predominantly rural area located 135 km south of Addis Ababa. On average, the district is situated at 2100 meters above sea level (with its overall altitude ranging from 1500 to 3400 meters above sea level). The climate is cool-to-cold in the mountainous parts and dry-hot in the lowlands. The first language of most of the population is a dialect of Guragigna, but Amharic is widely spoken and there is substantial interaction between

communities. The district under study has a population of 227,135, with over 100,000 between the ages of 15 and 45 years (CSA, 2007).

Butajira has been the site of an Ethiopian demographic surveillance site (DSS) for the last 25 years (Afework et al., 2014). Fertility rates in Ethiopia declined between 2005 and 2011, from 5.4 children per woman to 4.8, and then decreased further to 4.1 children in 2014.Total fertility rates are double in rural women compared to women living in urban settings (CSA, 2014; Tadesse & Headey, 2012). The DSS data show a high maternal mortality rate, high levels of adolescent pregnancy and only one third of women with optimal maternal care (Afework et al., 2014; Byass et al., 2008; Hogan et al., 2010). Ethiopia is one of major contributors of maternal mortality rate globally (Hogan et al., 2010; WHO & UNICEF, 2015).National data show that maternal mortality decreased from 871 to 676 Between 2000 and 2011, and to 497 in 2013 (Berhan & Berhan, 2014; Tessema et al., 2017; WHO & UNICEF, 2015).

3.3. Study population

Women of childbearing age (18 to 49 years) with an SMI (DSM-IV diagnosis of schizophrenia, bipolar disorder or severe major depression) and who were participating in the ongoing Butajira SMI cohort study were approached and invited to participate in the study.

The Butajira SMI cohort study was established between 1998 and 2001 in the Butajira district, southern nations nationalities of Ethiopia. The cohort study initially targeted 83,282 population in the town of which 68,378 was screened at base line of which 919 people found to have severe mental illness with additional 75 new case receptions to the cohort during the establishment years. Out of the total people with SMI (919), 347 were women who were in their reproductive age during the inclusion to the cohort (Alem et al., 2009; Fekadu et al., 2015; Kebede et al., 2003; Teferra et al., 2011) . During this study period (2014/15) only 188 women were in reproductive age, of which 113 of them participated in quantitative survey. The remainder have never responded to the questionnaire for various reasons such as amenorrhea for more than two years or reported menopause (N=24), unavailability at home in two visits (n=16), Permanent change in address (n=5) vagrant or living on street (n=4), Died (n=3), hearing difficulty (n=2) not volunteer or not giving consent (n=26) (Figure 3.3.1).

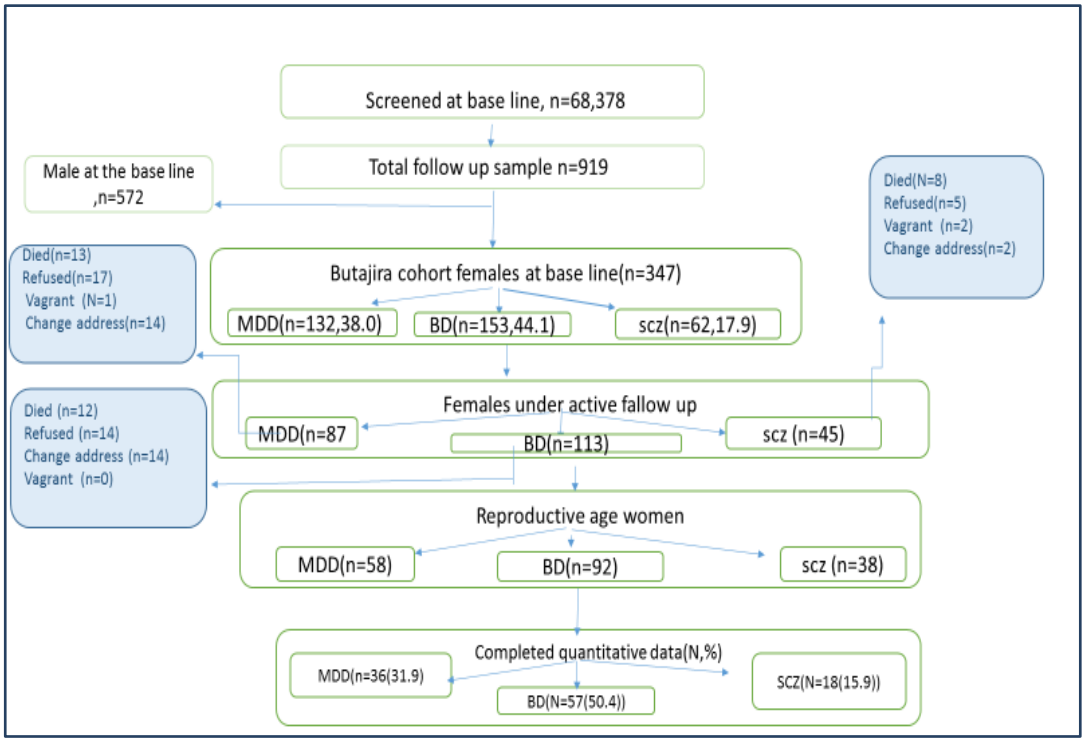

Figure 3.3.1 Schemata of sample selection

The quantitative questionnaire was introduced by experienced data collectors for reproductive age women who were in active follow-up phase of the cohort study. The intent was to elicit information on current family planning practices and preferences. It also aims at getting updated sociodemographic characteristics such us educational level, diagnosis, treatment and place of residence (rural vs. urban) based on which a sub-sample of women sampled purposively.

These participants have been followed up on a regular basis over the last 12 to 15 years, receiving free psychotropic medication and psychiatric care in the outpatient unit of the Butajira hospital from psychiatric nurses. The participants for this qualitative study were purposively selected.

3.4. Study sample

3.4.1. Study sample

The sample included women of reproductive age participating in the Butajira SMI

Inclusion criteria

- Women of childbearing age (18 to 49 years)

 Diagnosed with a severe mental illness (DSM-IV diagnosis of schizophrenia, bipolar disorder or severe major depression)

 Undergoing active follow-up in the Butajira SMI cohort study

Exclusion criteria

 Acutely ill

 Lacking capacity to give informed consent

 Unable to speak Amharic

Purposive sampling is a research process whereby individuals or groups with the required demographic, clinical or social characteristics are recruited to become parts of a study. In the present study, we purposively selected participants based on: 1) their current family planning practices and preferences; 2) educational level; 3) diagnosis; and 4) place of residence (rural vs. urban). Sample sizes for purposive sampling are not defined prior to data collection; instead they are determined by the sample size at which theoretical saturation is attained. Theoretical saturation is the point in data collection where new data are not bringing any additional insights to the research questions (Britten, 1995; Mack et al., 2005). In the present study, eight interviews were anticipated. However, more interviews were required in order to reach theoretical saturation.

3.5. Sampling procedure and interview procedure

3.5.1. Sampling procedure

Eligible women were approached by experienced project data collectors who explained the study and gave the woman an information sheet in Amharic about the study or read the information sheet aloud for women who were unable to read (Appendix B). If the woman agreed, the data collector obtained voluntary, informed written consent (See Appendix C) before introducing the short quantitative questionnaire (Appendix D). After quantitative data was collected, entered, cleaned and analyzed, the researcher proceeded to qualitative sampling.

3.5.2. Interview procedure

A mutually convenient time to meet was then arranged at the Butajira SMI cohort study project office or the psychiatric unit in Butajira Hospital. All interviews were conducted in Amharic (the official language of Ethiopia) as most of the Butajira cohort study participants speak Amharic. Furthermore, the principal investigator did not

understand the local language- Guragigna. Transportation cost was covered for participants and their attendants to come to the hospital.

In-depth interviews were then conducted. In-depth interviews allow for the exploration of individual subjective meaning, experience, beliefs, and attitudes through one-to-one interviews (Kitzinger, 1995; Whitley & Crawford, 2005). In-depth interviews may have a pre-defined theme, but the interviewer and interviewee are free to answer and discover whatever issues they identify as important (Brown & Lloyd, 2001; Razafsha et al., 2012). The intimate and open interaction which is characteristic of an in-depth interview can facilitate exploration of why people act in certain ways when it is a sensitive issue that may be less accessible in focus groups or other ways (DiCicco-Bloom & Crabtree, 2006). In-depth interviews differ from standard clinical interviews, by having a looser and more open structure which allows the participant to have as much control over the agenda as the interviewer (Britten, 1995).

The in-depth interviews elicited information about the women's family planning experiences and unmet needs for care (See Appendix E Interview guide). The interviews lasted between 35 minutes and an hour. In-depth interviews were carried out in a private location with confidentiality assured. Before we started the interview, the investigator asked the participant where they preferred to be interviewed and their choices were respected, for example in the office or outdoors under a tree. The interviews were audio-recorded if permission was given by the participant and later transcribed verbatim. Amharic transcriptions were checked against the audio files and the field notes taken by the psychiatrist who conducted the in-depth interviews before being translated to English for analysis.

During the selection and consenting process, the participants were clearly informed that they would participate in the study in their position as experts while the researcher would largely facilitate their experiences about family planning. The researcher also declared that the given questions have no right or wrong answer and those participants should take enough time and thought before answering. The researcher encouraged the participants to respond to the interview questions and contribute free of will and transparently in order to openly articulate their stories and experiences through their own voices.

This approach allowed the participants to emphasize their areas of concerns and priorities. As the researcher, I practiced active listening in the course of the interviews

with participants. I was encouraging their behavior through nodding, paraphrasing to facilitate common understanding on the meanings of their claims, seeking clarifications and summarizing. True, the interviews had an open-ended structure. Even then, the interview schedules (see Appendix E interview guide in English) has actually served me as a guide for the entire interview process. It allowed me to clarify issues and assisted me with the wording of questions.

During the interview process some clues for further information were generated from the informant responses. This has helped the researcher to pose more crucial questions and expound the scope for family planning and related issues at local level.

At the beginning of the interview, participants were asked to describe their living conditions in order to create a good rapport prior to discussing more personal information. One issue that arose was a lack of understanding about the definition of family planning. In order to address this, further explanation was provided in order to ensure consistency, since participants did not understand the term family planning or they tended to use different terms to those used in health facilities.

3.6. Data analysis

The qualitative data analysis for this study was conducted using the framework approach. This approach was developed by Jane Ritchie and Liz Spencer, from the Qualitative Research Unit at the National Centre for Social Research in the United Kingdom in the late 1980s for use in large-scale policy research (Gibbs, 2008; Ritchie et al., 2013; Ritchie et al., 2003) and is now used widely in health research (Green & Thurgood, 2013). The framework approach is an excellent tool for supporting thematic analysis because it provides a systematic model for managing and mapping the data (Gale et al., 2013; Smith & Firth, 2011). As described by Pope and colleagues, this approach encompasses five stages. The first is familiarization with the data by reading it thoroughly. Secondly, a thematic framework is identified. These themes were coded numerically. In the third stage indexing is carried out. This comprises organizing the subsequent data into the thematic matrix, where each part of data is represented by a numerical number and a short label. The fourth stage is charting, in which themes were charted and individual responses were entered under one theme. The last stage is mapping and interpretation. This stage is characterized

by linking phenomena and making sense of the whole process (Gale et al., 2013; Grbich, 2012; Pope et al., 2000).

Initially, interview transcripts were read for emergent themes, which were then being coded. Care was taken to ensure that the codes accurately captured the participant's meaning. A second researcher coded the interviews independently to ensure validity of the categories. The qualitative data analysis software Open code version 4.02 (Bourdon, 2002; Seale & Rivas, 2012) was used to facilitate systematic data management and analysis (Burnard, 1994). These software packages allow for effective and efficient coding of themes and categories, and also for easy retrieval and movement of data between documents when compared with manual handling of qualitative data (McLafferty, 2006).

3.7. Ethical considerations

3.7.1. General ethical considerations

Women with SMI are potentially vulnerable participants. In this study, the participants were informed of the nature and aim of the research and their capacity to give consent was assessed. The PI of the study, who is an Ethiopian psychiatrist, completed a structured assessment of the person's capacity to consent to participate in the study (see Appendix F).

Participants with the capacity to consent were informed about the research and invited to give written consent (See Appendix G). The study was explained in the official language of Ethiopia, Amharic, and participants were encouraged to ask questions before being formally asked to sign the consent form. After they signed the consent form, they were informed again that they could ask questions at any time and could also withdraw from the research or end an interview at any stage without any adverse consequences to them. Agreement was asked of the participants to audio-record and transcribe the interviews. They were assured that the principal investigator and the transcriber were the only persons listening to the audio-recordings and that only my supervisors, Dr. Sorsdahl (UCT) and Dr. Hanlon (AAU) and I were reading the transcripts.

The identities of the participants were kept confidential. Their names were not known to anyone except my supervisors and the PI. The researcher also oriented the participants about the anonymity of their information shared during interviews. It was also clearly ensured that private password-protected computer of the PI will be

employed to secure storage of the interview recordings and transcriptions. The privacy of participants was ensured during the interview. No compensation was p to participants, except for a contribution towards their travelling expenses, and they were informed of this. Written, informed consent (See Appendix G) was obtained from participants before commencement of the interviews. The principal investigator read out the information sheet (See Appendix H) for those who were unable to read. Each participant was given an information sheet to take with them.

Ethical approval was obtained from the University of Cape Town's Human Research Ethics Committee (HREC REF:265/2014) as well as local, ethical clearance from Amanuel Mental Specialized Hospital research and training directorate ethics review board before data collection started (Appendix I).

3.7.2. Specific ethical considerations

The interviews were not rushed and maximum care was taken not to overwhelm the participants. Only one question was asked for a participant at a time. The interviewer was also very sensitive to the interview's emotional effects on the participants. If participants became distressed during the interviews, they were offered a break from the interview and were also asked whether they wanted to continue or not. Participants were informed about opportunities for additional professional support mechanisms in case the abuse is continuous or may possibly endanger their immediate safety. The interviews were conducted in the Butajira cohort study project office or wherever the participant was more comfortable about their privacy. The interviewer sat on the same level as the participant so as to indicate with her physical presence that she was not taking on the role of the expert in the interviews. Two of the interviews were conducted outside and in these interviews care was taken to ensure that the participant and the interviewer were sitting at the same level.

The interviewer assured participants of the availability of professional support from the principal investigator in cases of distress before commencement of the interview. This has greatly helped to mitigate or avert the already lower risks associated with the participation in this research

Chapter Four: Research Results

The research results are presented according to the four major themes that emerged from the data analysis: 1) the broader context of intimate relationships and sexual life of women with SMI; 2) attitudes towards childbearing in women with SMI; 3) experience of family planning in women with SMI; and 4) preferred family planning services. After describing the characteristics of the participants who participated in this study, this chapter will consider each theme in turn.

4.1. Participant characteristics

In-depth interviews were conducted with 16 participants. The age of the participants ranged from 23 to 40 years old. More than half of the participants were unable to read or write (N=9). Most of the participants described themselves as housewives (N=11), or unemployed (n=4), with the remainder reporting craft work and petty trade activities. The majority of participants were single (n=10) and residing in the rural area (N=11). The diagnoses of the participants, as provided by the Butajira cohort study, according to the DSM IV-TR were schizophrenia (n=4), bipolar disorder (n=6) and severe major depression (n=6) (see Table 4.1).

Table 4.1 Descriptive Characteristics of Participants (n=16)

Characteristics	Frequency	%
Age (mean, standard	35.3 (6.23)	
Diagnosis		
Schizophrenia	4	25.0
Bipolar disorder	6	37.5
Major depressive disorder	6	37.5
Marital status		
Single	7	43.8
Married	6	37.5
Separated	2	12.5
Divorced	1	6.3
Residency		
Rural	11	68.8
Urban	5	31.3
Education		
No education	9	56.3
Informal	2	12.5
Formal	5	31.3
Occupation		
Housewives	11	68.8
Self employed	2	12.4
Unemployed	3	18.8
Taking psychotropic		
No	7	43.3
Yes	9	56.3

4.2. Context of intimate relationships and sexual life of women with SMI

Many of the participants perceived that their mental illness had impacted upon their personal relationships. They felt that people in the community did not consider a woman with SMI to be a person fit for friendships, intimate relationships and a sexual life. They reported that women with a mental illness were defined and stigmatized by their illness, with this being considered to be the only thing worth their focus in life their illness. Not only was this prejudice held by community members, but also shared by some of the health care professionals. Many of the women themselves endorsed the view that their mental illness should be the only concern in their life. Such attitudes led to a disruption of their relationships, if they had any. Many of the women spoke of such experiences:

They [people] think that a mentally ill woman doesn't have extra needs beyond thinking about her illness.

Single woman with schizophrenia (ID07)

Since she is mentally ill, she is considered as good for nothing and not able to get a man, to marry her.

Single woman with bipolar disorder (ID14)

One woman articulated her dismay at her stigmatization and exclusion:

My friends ignored me… because I have a mental illness… nowadays I only have one friend.

Single woman with bipolar disorder (ID11)

A number of participants reported that women living with an SMI were highly vulnerable to abuse and sexual assault as a consequence of their illness. Others added how mental illness compromised women's ability to fight for their rights, and were forced to engage in behavior they were not comfortable with. Even worse, a number of participants reported that they had been the victim of sexual violence or assault. Respondents described situations where men coerced women with SMI into engaging in various sexual acts. In the following excerpt, the woman describes not only her experiences of rape but also the indifference of others to her plight:

He [a relative of the woman] was at his home; he raped me and then made me have a baby: he did not marry me legally. Rather, he forced me at my adolescent age… nobody was there [In the compound] …that day… I was suffering in pain When they came back home …, they made coffee for themselves; nobody remembered and asked me what happened to me

Single woman with bipolar disorder (ID11)

Another woman with schizophrenia was also coerced into sexual contact:

… I have a small cottage and I have a small piece of land. I do my own work while I was living like this until one day he forced himself on to me, I didn't like him, I didn't will it, he didn't talk to me.

Single woman with schizophrenia (ID02)

Another woman spoke of knowing her vulnerability but still unable to mobilise others to protect herself from sexual assault*:*

I asked my cousin to go with them [to the ceremony] or send me to my mothers' home because this boy [her brother] might harm me. They didn't allow me. I stayed at home. At that time, I was on the medication which made me sleepy and I couldn't hear anything, as if I am dead. I felt that it was in my dream. When I woke up I was soaked with blood and I was in pain.

Single woman with bipolar disorder (ID16)

Similarly, another woman spoke of the particular vulnerability of having SMI which contributed to a man raping her:

When I was sick, someone who was living in our village deceived me. He told me that he would take me and marry me. He is a friend of my brother. Then he played tricks on me. Then, when my brother intimidated him, he stopped his action… When I got angry at home, I did something… I went out from home. It was at night and he forced [raped] me; he knows that I am mentally ill.

Single woman with bipolar disorder (ID12)

This woman went on to say:

… I was raped twice while I was sick. It is because of that I gave birth…I gave birth without marriage… It was by accident without my consent, I was forced.

But, once it happened, I decided to bring them up.... It is the same for both children

Single woman with bipolar disorder (ID12)

Furthermore, for many of these women sexual assaults brought them unwanted pregnancies. The woman who had been assaulted by her half-brother spoke graphically of the assault as being like death for her:

I have a child from my brother…. It is embarrassing when your brother killed you and he lives his comfortable life. He went abroad a few days after he buried me [Forced me].

Single woman with bipolar disorder (ID16)

Many participants observed that often people would comment negatively when a woman with SMI gave birth to a child after being sexually assaulted. No one considered the psychological and social difficulties faced by these women. The participants perceived that the community was judgmental towards women with SMI in this situation. For example, a homeless woman with SMI who had a child following a sexual assault was seen in the same way as a healthy woman who had a child out of wedlock. Two participants (one married and the other single, respectively) who had given birth recounted what people had said to them:

They say "You are mentally ill and you give birth to a bastard?" and she replies "I am on the line [I am homeless]. What can I do?" They say "How can she give birth while she has mental illness?"

Married woman with bipolar disorder (ID06)

They insulted me in front of me …. How she can give birth being mentally ill?

Single woman with bipolar disorder (ID11)

Other women also described how their intimate relationships had been negatively affected by mental illness. When their partners discovered that they had a mental illness or they witnessed a relapse, their relationships came to an end, either by separation or divorce. Whether this was a formal or informal relationship, the outcome was usually the same:

He left me alone. He didn't say a word, he left town, and he hid after he knew I gave birth and…. Umm that occurred to me when he knows I am mentally ill.

Single woman with schizophrenia (ID02)

When I got ill, things did not go as he [my husband] had said. He left [the country]

…My illness relapsed. The man said that it was such a burden that my illness relapsed… He said that he is old and that he is not willing to deal with it at his age…. I married twice; they left me because of my illness.

Divorced woman with bipolar disorder (ID04)

4.3. Childbearing in women with SMI

Participants had various concerns about child bearing in women with SMI, such as a fear of relapse of the illness during birth or after delivery, being unable to raise their children and difficulty in parenting, and the effect of the medication on their child. For all these reasons, most (n=11) participants reported that women with an SMI should not give birth.

The most frequently reported reason for a woman with SMI not to give birth was the risk of relapse. Participants tended to attribute the relapse of the mental illness in the post-partum period solely to the existing mental illness. Participants did not mention the role and impact of psychological and social factors. One participant shared her experience of illness relapse in relation to childbirth and spontaneous abortion:

… When I was still having children, I used to suffer from my illness… it is better if she [woman with mental illness] doesn't give birth… I was suffering because of repeatedly giving birth. I was sick after almost all my deliveries…When I got pregnant and whenI gave birth, my illness got worse…It is not only giving birth. Once I had a spontaneous abortion and my mind got very sick… (Mother of Eight)

Married woman with major depressive disorder (ID01)

Another woman shared a similar experience:

I have a mental illness. It relapsed when I delivered. I am very sick now, this year it's worse. Giving birth isn't good with my mental illness… In my opinion; the child should have not have been born. When giving birth, the mental illness starts again… Yes, I got sick. That's why I say I don't want to have children.

Married woman with major depressive disorder (ID09)

One participant described her interaction with her children as the specific reason for the relapse of illness, although she was the only woman to relate to such an experience:

When the children irritate me or when they disturb me, it just doesn't feel right. I become sick. …I just feel anxious… And whenever I am breast feeding, I feel so unwell.

Married woman with Bipolar disorder (ID06)

Aside from relapse, the second other major concern about childbearing was about not being able to care for their newborn baby. A number of participants reported that they were not able to provide adequate care, for example, with housekeeping and cooking, when their family support was either inadequate or non-existent. However, these worries were focused predominantly on the physical needs of the newborn. Emotional aspects of parenting were not mentioned by in the study participant:

…. Yes, it's hard, it's even harder to manage ourselves let alone a child……A child cannot take care of himself. He can't keep himself clean or he can't even feed himself.

Single woman with schizophrenia (ID07)

……*its difficult having kids while being mentally ill…..a child can't take care of himself, can't cook…. how she can do that if she is sick?*

Married woman with major depressive disorder (ID 05)

Even if raising children is a challenging task for all parents, women with mental illness spoke of being more burdened. Child raising was perceived as the most difficult task to shoulder. This was emphasized as an additional reason for why women with an SMI shouldn't give birth:

Raising children and mental illness are troublesome… Raising children is as troublesome as the illness. I prefer she would not give birth…… Yes, raising children is as stressful as the mental illness for women an SMI…. So, I would advise they don't give birth at all…. giving birth…. It is adding another stress on top of the mental illness.

Married woman with bipolar disorder (ID06)

Another woman with bipolar disorder described child rearing as:

It is a dual burden for a woman living with the illness: illness and childbirth

Single woman with bipolar disorder (ID14)

A divorced respondent woman with SMI further reaffirms:

First of all; they [children] would have driven you crazy. When their children give them a hard time, they tell me I am lucky Allah did not give me any children.

Divorced woman with bipolar disorder (ID04)

Some of the respondents expressed that they lacked confidence in their ability to care for a newborn child. As described above, taking care of a newborn (and a child) was considered to be an arduous task by many. Linked to this, some women said that a woman with mental illness could only have a child if she had an understanding and supportive family:

She [a woman with mental illness] needs to get help from family members. … I will consider it conducive only if she has a family member who will supervise them and taken care of them.

Married woman with bipolar disorder (ID06)

One with support and care, one with a comfortable life may give birth. What problem would [she] have? … Anyone with a comfortable life can raise [the child]. But what would someone with no comfort or poor health have? How would you have comfort if you do not have any health?

Divorced woman with Bipolar disorder (ID04)

Not all participants had a negative view of child-bearing in a woman with SMI. Some participants reported that having a child might indeed improve their situation. One of the participants even described how the symptoms of her illness improved after she gave birth. This respondent also spoke of women she knew who had a mental illness and were able to care for their children irrespective of their illness:

… there are some people who manage to take care of three or four children while they are still very ill. Do you know 'y'? You might not …and she has three children but she is very ill. Even though she is very sick, she manages to take care of her kids… people say "a mad person is not going to take care of his/her kid..." but they can! There is the saying in our area "mad people and cats don't forget their child"

Divorced woman with schizophrenia (ID08)

Another woman described how she improved after having a child*:*

I heard that getting married and having kids would renew your mind and give you relief. I took their advice and I got married and gave birth. Even though my first child died while he was in my womb, I gave birth to my current child. Thanks to God, I am fine now. Before I gave birth, I used to get sick and worry a lot. Although, we are poor and have very little to eat, when I spend time with my daughter, I feel better… yeah, I used to get sick a lot before. I used to talk alone. I had had a lot of stress and get disturbed easily, but now I am a lot better because I spend a lot of my time with my daughter.

Divorced woman with schizophrenia (ID08)

Most participants spoke of the economic disadvantages experienced by women with an SMI. All participants agreed that a woman who gives birth to a child should be in good health and able to earn money. Otherwise the woman's resources may not be enough to care for both her own health and the health of the baby. For many, the economic burden was the main reason that a woman with mental illness should not give birth. Most of the participants were economically dependent on their families and did not have their own income. A single woman's experiences illustrate this:

I am ill and I am sick, with what money will I raise a child? I was worried and thought of killing myself when I gave birth. But Allah will ask me for my soul. Besides my father is poor and he is very old.

Single woman with schizophrenia (ID02)

Similarly, another participant spoke of her experience subsisting on a day-to-day basis:

……Sometimes people feel sympathy for me so they give some money (five or ten birr) and sometimes I sell some lemons and buy some bread for the children with the money I get…This how I try to live daily.

Divorced woman with schizophrenia (ID08)

Another participant also spoke of the harsh economic context:

When you have many kids, you don't have enough for clothing or food… you don't have enough for food…. And when the child is young you need to take care of both the child and yourself.

Married woman with major depressive disorder (ID05)

Only one participant expressed fears that she might give birth to a child with health problems because of exposure to medication taken for the mental illness. Despite her concerns, this woman had never raised this issue for discussion with a health professional or others, and no one had given her any information about this issue:

She [a woman with mental illness] is on psychiatric medication and if she gets pregnant and gives birth, what is going to happen to the newborn, is he going to be mentally retarded or normal? I only ask myself about this, I never ask or talk with the health workers or with others.

Single woman with bipolar disorder (ID15)

All of the participants reported that most families, the community and few health professionals were of the view that a woman with mental illness should not have children. This was perceived by the women as a negative attitude and not only advice given for the sake of their health. One participant highlighted the paradox of being condemned for getting pregnant on the one hand, but on the other hand, having little control over whether or not she becomes pregnant as follows:

……. *How can she get pregnant if the illness doesn't disappear? God's work… People talk, saying why she didn't get contraceptive injections and why she wanted to have children since she is ill… but pregnancy can come against her will by force… all people say no giving birth if she is mentally sick*

Married woman with bipolar disorder (ID01)

Two respondents recounted the gravity of domestic cultural violence that may even subject women with SMI to honor killing, merely for having a baby:

The family carrying the ill woman, if she brings the child they will kill her, they say she shouldn't give birth…. I say it is not necessary for her.

*Single woman with bipolar disorder (ID*10)

…. It's expected that people who are ill are insulted when they give birth…. They [people] say, how can she give birth unless she is better? How can this be acceptable?

Married woman with major depressive disorder (ID13)

Participants reported that the community attitudes towards women with SMI who give birth made it more difficult for them to care for their children. They described how stressful such an experience would be for a mother with a mental illness.

…local community even clearly says" a mentally ill like her! how could she give birth; how could she raise a child without even knowing what is good and bad for herself; how can she have a child? …. They openly say women with mental illness shouldn't have children at all because they just cannot handle them. It is very difficult even to imagine!"

Single woman with schizophrenia (ID07)

4.4. Family planning experiences and awareness in women with SMI

From most of the participants, there was initial resistance to talk about their knowledge of family planning which appeared to be related to the sensitivity of the topic. Most of them equated family planning with prevention of birth, rather than planned birth, and referred only to contraceptive interventions. Injection, pills and condoms were the contraceptives which were widely recognized by the participants. Only a few of the participants expressed awareness about implants and intra-uterine contraceptive devices. None of the participants had ever heard about emergency contraceptives. Some women expressed the view that the concept of family planning refers only to limiting the number of children an individual has, but does not include controlling the timing of pregnancy:

Some participants reported that they did not know about contraception. One participant justified her lack of awareness as being due to her status of being single:

… I don't have an idea [about family planning], and also, I am not married…

Single woman with bipolar disorder (ID 12)

As described above, although condom use was generally recognized as a means of contraception, condom use was more often linked to promiscuity and preventing transmission of sexually transmitted diseases (STDs) rather than an intervention used in family planning. The belief in the negative associations of condom use is conveyed by the following statements:

I have heard about it [condom] but I never had affairs. This is my first husband. I never had an affair. I have been living with him. I don't know anybody else.

Married woman with bipolar disorder (ID06)

Condom means… indecent people use condoms; these people use them to create temporary relationships… To protect themselves from different problems, when they are in temporary relation. They are ill-mannered. They used it in hotels….

Single woman with bipolar disorder (ID15)

The majority of participants expressed inconsistent knowledge about contraceptives and some of them displayed concerns and apprehension about side effects. Despite

this they reported that contraceptives were important in preventing pregnancy and expressed a positive attitude towards its use:

If I don't use these things [contraceptives], then I'm going to have a bastard /illegitimate child… it refers to an unwanted child without a father. But sometimes even if the father is there, he might not be supportive. … Well, it is the child with no father that you conceive with a random guy and bear it without your interest.

Divorced woman with schizophrenia (ID08)

For me, a woman living with mental illness shall use implant earlier or, if she wants to have sex, she shall use pills or injection so that she can prevent extra mental health complications associated with such issues.

Single woman with schizophrenia (ID16)

One participant expressed her regrets at not having had adequate information about family planning and its accessibility in their respective area. She described that the lack of information causes a huge impact on her personal and family life.

If I had known [about contraceptives], it would have been good for me… good for my mind… its good for my children. My condition got worse when I give birth. If I had known, it would have been good… for my sons… if they had brought it to me… I should have learnt a lot of things, my family suffered a lot when I am sick.

Married women with major depressive disorder (ID01)

Misconceptions about family planning were evident. A majority of women considered contraception to be the only role of family planning. Some of the participants considered the definition of family planning to be only caring for the family and managing household activities:

… *They say it is managing your home properly, caring for the family keep your hygiene, don't sleep wearing clothes, sleep just wearing night clothes, care for your children.*

Single women with bipolar disorder (ID11)

Two participants considered family planning to be specifically important for commercial sex workers. This misconception may hinder utilization of family planning. The participant expresses her understanding as follows:

I think it [Family Planning] is a business. …. Business is going to males to get money…. Women who do that, they know well about it because they afraid to get pregnant.

Single woman with bipolar disorder (ID12)

No woman spoke of being forced to use contraception because they were mentally ill. The main issue was that they were not able to obtain family planning services when they needed them because nobody made an effort to give it to them and they experienced insurmountable barriers to accessing family planning in primary health care. As a consequence, many of the participants spoke of the gap between their need and the availability of reliable information about contraception and access to the different methods of family planning. One respondent clearly reflected upon the dilemmas surrounding risks of taking contraceptives and psychotropic medication:

……. How can I take that [the contraceptive]? I am on a drug for mental illness. I can't add more drugs. Since I am on a drug for mental illness, I told them [health professionals] I can't take another drug. I told them I can't. They did nothing…… They left me. They said "you may give birth if it's God's will, if not it's his work" they kept quiet. They said I can't take the drug…… Drug for mental illness is heavy; they [health professionals] said it's difficult to take both.

Married woman with bipolar disorder (ID03)

Not only were women with SMI vulnerable to sexual assault but also less aware of how to access to family planning resources. In relation to this double jeopardy, one respondent clearly laments:

If I knew that [preventing unplanned pregnancy] would have been good, but I do not know, I can only think about myself, who am I to think about others? I couldn't even do my job, I stayed at home, I couldn't hang out with neighboring women, I stayed home it was hard time still it is hard to me.

Single woman with schizophrenia (ID02)

Another woman alluded to the inconsistencies in family planning approaches:

…. There are times where I took the contraceptive pills…. My mother used to take the pills, back then, I used to take her [my mother's] pills, whenever I had unexpected sexual intercourse.

Divorced woman with schizophrenia (ID 08)

No participant was forced by a health professional to take contraceptives in this study. Indeed, one of the participants recommended protecting women from victimization by institutionalizing women with SMI and forcing them to use contraceptives:

I prefer the government institutionalizes the women and take care of them. The women might not agree. But if they agree, that would be better. They can be rescued from all the compounded suffering- the mental illness and taking care of unwanted kids. … women with SMI should be institutionalized and forced into taking contraceptives. … I think it is better if [women with mental illness] are coerced into taking it. … The illness and giving birth is a struggle. So, if they don't have a family, they should be institutionalized and given the medications.

Married woman with bipolar disorder (ID06)

Another respondent responded with sarcasm:

…. The other reason is because I am mentally ill, how could they [health extension workers] think about a mentally ill woman and tell her about birth control? They think that a mentally ill woman doesn't have extra needs beyond thinking about her illness.

Single woman with schizophrenia (ID07)

It was reported how difficult it could be for women with SMI to disclose to others that they were sexually active, let alone to broach the topic of contraception. This was

particularly the case if a woman with an SMI was not married. Three women described their experiences as follows:

It is embarrassing…… I have a mental illness and also, I am not married. How can women like me talk about contraceptives? It is shameful to do that…

Divorced woman with bipolar disorder (ID04)

How could I ask for birth control when I am mentally ill?

Single woman with schizophrenia (ID02)

They say 'why does she need it; why doesn't she treat her illness? … They say 'she wants to use contraception even though she has a mental illness?'

Single woman with Bipolar Disorder (ID10)

4.5. Preferred family planning services in women with SMI

Most of the study participants discussed that family planning services should be accessible for all women living with a mental illness. They spoke about the need for accessibility and privacy, and raised concerns about stigma, lack of adequate knowledge about family planning, and the need for special considerations in the family planning service. When asked how they would prefer the family planning service to be delivered, a woman replied:

… If it [Family planning service] is given equally to all… yes, but it is difficult for unmarried and mentally sick woman to use the service freely.… They say, why does she need it? Why doesn't she treat her illness?

Single woman with bipolar disorder (ID10)

The participants also discussed the need for improving awareness about family planning services among women with SMI, their families and community. They emphasized the need for special advice, care and support from the family, community and health professionals:

Health extension workers should teach us and our family. … They [women with SMI] need to get frequent advice and teaching… Yes, education is good. For a mentally ill women family planning would be good when they give time just like you have given me now and when they ask us and when they help us to understand, until now nobody has done this, this is my first time.

Single woman with bipolar disorder (ID10)

Most of the participants affirmed that women with mental illness needed special attention, advice and counseling. They also mentioned additional support for women with mental illness to be crucial. Most participants preferred to be provided with family planning services in a mental health clinic and by a mental health professional. The reason given was the need for the person advising on family planning to have adequate knowledge about mental health. The participants discussed this as follows:

…. There has to be special advice for them [women with SMI]. … They need to have an advice by physicians here [Psychiatric clinic] that has to be provided to their [women with SMI] family and their neighbor about the need for family planning for women like me. … If there is a bad neighbor, he/she may aggravate the illness. They insult and humiliate you if you give birth or go to the birth control service. So, in such a situation, it is essential that mental health professional should also sensitize neighbors as well. …… because they are ill I would suggest, it is essential to advise and teach with great patience of these women.

Single woman with bipolar disorder (ID14)

We [women with SMI] need extra support, like advising and teaching slowly, as we don't have faster functioning in understanding lessons/things. But I still insist it is good if mental health physicians could teach us so persistently and with utmost perseverance.

Single woman with bipolar disorder (ID10)

On the strategy of inclusion of family planning service to mental health care, a single woman urged:

It is better if it goes parallel, what I mean is it is good if it can go together. … It is better if it is the same professional. …It will be appropriate if it can be one for mental health and one for family planning but both should have mental health background.

Single woman with bipolar disorder (ID15)

Others clearly favoured delivery by mental health professionals*:*

I think it would be better if it is given here, when I come here [psychiatric OPD] for my follow up I could also get the family planning service… If the service is here we will get both medications here, we won't have to go to different places

Single woman with schizophrenia ID02

Some participants preferred that the role of health extension workers be given to psychiatric nurses:

It's the health extension workers who travel from house to house to give birth control [contraceptives]. It's better for us if it was a mental health professional.

Married women with major depressive disorder (ID09)

Although most of the participants preferred to receive the service integrated with their mental health care, others suggested their home as another alternative service area for family planning in women with SMI. The reason for this being that it would reduce the distance they would be required to travel and it would ensure privacy and confidentiality. These views are encapsulated by the following statements:

I prefer if the mentally ill women could get it at home. I mean, if she could be given at home in the morning. … I choose she is given at her home. … Hmm…. I prefer it that way. … It is better that way.

Married woman with bipolar disorder (ID06)

Most of the participants also recommended a separate family planning service area for mentally ill women, which would protect their privacy. Most had seen family planning services provided in a group format and expressed that they would be afraid to ask questions and may find it difficult to understand the discussion as well as other group participants.

For me, it would be good to provide counseling separately for a woman living with mental illness on such issues … the possibility of becoming a mother, … If you advise them in a group, it is difficult for them to ask questions and also, they may need additional time to understand what it has been said.

Married woman with major depressive disorder (ID 09)

In addition, there is a privacy problem. Women say this situation makes them to be frightened. It is just like that. It is conducted in a group.

Single woman with bipolar disorder (ID 14)

It should be in private it's scary when it's in groups…Yes, and when she comes in the countryside to my house I can talk to her on private… I want to talk in private and also get the medication in private. That's how I am… yes, if they all speak to experts like you in private it'll be good if they would give me the medication in private and also speak to me that way.

Married woman major depressive disorder (ID05)

Participants emphasized that women with SMI need awareness about, and access to, emergency family planning services. Most of the participants expressed their interest in emergency family planning service as they are a vulnerable group

Chapter Five: Discussion

In this qualitative study from rural Ethiopia, perspectives on family planning and unmet needs for care were explored in women diagnosed with SMI (schizophrenia, bipolar disorder or severe depression) in a rural Ethiopian setting. Four major themes emerged: (1) the broader context of intimate relationships and the sexual life of women with SMI, (2) childbearing in women with SMI, (3) family planning experience and awareness in women with SMI, and (4) preferred family planning services in women with SMI. These findings will now be discussed in relation to the existing literature. Thereafter, policy, practice and training implications are discussed. This chapter concludes by addressing possible areas for further research.

5.1. Major findings

5.1.1. Intimate relationship and sexual life of women with SMI

In the present study, participants emphasized the pervasive effect of SMI upon intimate relationships and the sexual life of women. The study participants noted that women with SMI, although commonly deprived of the opportunity to exercise their biological needs and social rights, tend to run much higher risks of victimization and/or sexual exploitation. Some of the respondents spoke of their experiences of sexual assault, either at the hands of extended family members or strangers. They described being silenced for lack of proper legal protection and suffering due to their lack of access to contraception and/or other family planning resources. The participants in this study also perceived a reduced chance of having a lifetime partner.

These findings are consistent with studies on women with SMI from other parts of the world. For instance, Borba and his colleagues conducted a qualitative study with poor urban Africa American women living with an SMI. This study reported a multitude of social disadvantages that were experienced by these women such as isolation, poverty, and unemployment (Borba et al., 2011). Another study from India found that community members held negative attitudes about men marrying a woman with an SMI (Sharma 2015), while a study from Turkey found that women with SMI held negative perceptions about marriage, sexuality, family planning, child bearing and pregnancy, compared with women without SMI in the general population (Özcan et al., 2014). A systematic review that included 84 studies on the reproductive health care practices of women with SMI concluded that SMI in women was associated with low utilization of family planning and other reproductive health services, including the

use of contraception (Matevosyan, 2009). Women with an SMI were more likely to have multiple sexual partners in their life time, unplanned pregnancy and a higher risk of STD then women in the general population (Matevosyan, 2009).

Women with SMI have a greater risk of victimization compared to women without mental illness (Goodman et al., 2001; Khalifeh et al., 2015a; O'Hare et al., 2015; Tsigebrhan et al., 2014). They have much higher risks of sexual abuse and post-traumatic experiences, which in turn can aggravate the mental illness (Bonugli et al., 2010; Mauritz et al., 2013; Mueser et al., 2004). Exacerbations of mental illness could limit the power and ability of women to control their own sexual life, which further increases the risks of unplanned pregnancy. Findings from other studies also underline the complex set of sexual experiences of women with SMI (Dvorak et al., 2013; Gearon et al., 2003; Khalifeh et al., 2015b; Ramrakha et al., 2000).

Women with SMI in this study also perceived stigmatizing attitudes from the community (Barke et al., 2011; Kabir et al., 2004) and also endorsed some of the negative stereotypes themselves (Girma et al., 2013). As a consequence, the participants felt that they were not desirable as romantic or sexual partners. This situation in turn tended to have justified their social exclusion from decisions about child bearing and/or utilization of contraceptives and other family planning amenities. The women in this study appeared to harbor negative attitudes about their own sexual life thereby limiting the quest for partnership options. It may have been that the women anticipated rejection by potential partners and avoided intimate relationships due to their mental health problems.

Furthermore, the stigma towards women with SMI limited their utilization of reproductive health services and their chance of having a stable intimate relationship. Participants of this study further indicated that they have been internalizing the social stigmatization about their deprivation of sexual and reproductive life as fate or a matter of life's destiny which cannot be changed (Buckley et al., 2009; Goodman et al., 2001; Meade, 2006; O'Hare et al., 2015).

5.1.2. Childbearing in women with mental illness

In the present study, a majority of the participants believed that their risk of unplanned pregnancy was much higher than other women in the community. This finding is consistent with numerous studies conducted in both HIC and LMICs (Gold et al., 2007; Khan et al., 2016; Miller et al., 2015; Robinson, 2012), that found a higher prevalence of unintended pregnancy in women with SMI and that consideration of this issue during mental health practice improved mental health outcomes. In the current study, participants expressed fears about relapse in the context of child bearing. As evidenced by many studies, delivery appears to be one of the factors most likely to increase the risk of relapse in women with SMI (Cohen et al., 2006; Di Florio et al., 2013; Harlow et al., 2007; Munk-Olsen et al., 2009; Vigod et al., 2010). This perception in turn affected the community's view of childbearing as risky for such women. However, many respondents explained that this attitude was motivated in part by concern for the woman and fears that she would become more unwell if she added pregnancy to her existing mental health problems.

Contrary to the evidence that discontinuing medication during pregnancy opens up the possibility for relapse in women with mental illness (Boden, 2012; Buchanan et al., 2010; Yatham et al., 2006), participants did not mention the risk of relapse associated with drug discontinuation or special treatment needs during pregnancy. Instead women emphasized the stresses associated with child-bearing, such as inadequate sleep, nutrition and support. However, although the women in this study had access to psychiatric nurse-led out-patient care, this centralized service was unlikely to meet the needs of perinatal women with SMI adequately. Expectations of even specialist mental health services in Ethiopia have been found previously to be low (Aberg et al., 2014; FMOH, 2012; WHO, 2011) and this may be a barrier to improving care for perinatal women with SMI.

In this study, there was also perceived concern from the community about the impact of pregnancy in a woman with SMI on her family, with the assumption that she would rely on them to care for the baby (Shibre et al., 2003). Studies from the same rural area of Butajira found that women with SMI may experience some functional impairment due their mental health symptoms, which could be exacerbated by additional factors such as poverty and lack of supportive comprehensive health services (Habtamu et al., 2015). These problems could be further compounded when all the responsibility of taking care of the new baby and the mother tend to pass to the immediate family circle (Habtamu et al., 2015; Kebede et al., 2003; Vasudeva et al.,

2013). In the current study, participants indicated that the mental health needs of women with SMI and lack of independent income left the burden of support exclusively upon their extended family networks. This finding concerning reliance on the family is consistent with many other related studies conducted elsewhere in the world, including the rural areas of Ethiopia (Martinez-Aran et al., 2008; Muir et al., 2008; Shibre et al., 2003; Zergaw et al., 2008).

In spite of the wealth of evidence about the effects of psychotropic medication, particularly mood stabilizers on the fetus, and the importance of discussing medication risks for reproductive age women with SMI, such discussions are not common practice (Berard et al., 2010; Campbell et al., 2014; Diav-Citrin et al., 2014; Kulkarni et al., 2015; Veiby et al., 2014). In the present study, the women appeared to have had little or no discussion about medication with the mental health professional providing their care. This finding is consistent with studies from HIC (Henshaw & Protti, 2010; McLennan & Ganguli, 1999).

A number of studies have found that the act of parenting is highly stressful for women with SMI in high income country settings (Beardselee et al., 1998; Harden, 2005). A few limited studies from low income settings have described how SMI can affect parenting in various ways. These studies suggest that providing acceptable care for their children is not easy for mothers with SMI due to their illness, (Gelkopf & Jabotaro, 2013; Kahng et al., 2008; Rampou et al., 2015). Participants in the current study also highlighted how parenting can be challenging for women with SMI.

Despite the daunting socio-economic challenges discussed so far, recent studies have explored the likelihood that women with a SMI will become parents and raise children by themselves (Diaz-Caneja & Johnson, 2004; Oyserman et al., 2000). The women in the present study also supported this conclusion. Some of the women in this study believed that having a child and the act of parenting would have a positive impact on their mental health. A study conducted in US found similar results, where women with a mental illness believed in their efficacy in parenting and considered child bearing to be a panacea for their difficulties (Mowbray et al., 1995). In Ethiopia and other African countries, having children is viewed as having a positive impact on a woman's social status and is highly praised in the context of formal marriage (Deribe et al., 2007; Hollos et al., 2009; Rouchou, 2013).

5.1.3. Family planning experiences and awareness in women with SMI

Several studies in Ethiopia indicate that knowledge about family planning in the general population has increased significantly, albeit with persisting low levels of uptake and a high proportion of women still reporting unmet needs for family planning (Ayele et al., 2000; Beekle & McCabe, 2006; CSA, 2014; Korra, 2002; Medhanyie et al., 2012). The present study found similar findings where, despite positive attitudes towards contraceptives, contraceptive use remains inadequate. In the case of women with SMI in this study, the gap in family planning utilization resulted from a range of obstacles, including lack of information, inaccessibility of the service, low awareness of caregivers about the needs of women with SMI for family planning, stigmatizing community attitudes towards family planning for these women, lack of integration of family planning within existing mental care and perceived stigma from health care providers.

Women's lack of adequate knowledge about family planning and fear of side effects played a role in the decision to use contraceptives. This included the misperception that contraceptives could induce blood loss (menorrhagia), weight loss and other negative side effects which considered as inevitable rather than rare. This misunderstanding has implications for the uptake and discontinuation of contraception and accords with previous reports from Ethiopia (Alemayehu et al., 2015; Beekle & McCabe, 2006; Grunebaum et al., 1971; Guedes et al., 2009; Tekelab et al., 2015).

The most common reason for using family planning for women in the present study was for preventing pregnancy rather than birth spacing. This finding is similar to a study conducted in Nigeria where women with SMI reported that pregnancy prevention is the goal despite that the timing of having a baby was the most important problem faced by women in rural communities (Tunde-Ayinmode, 2013).

In the present study, a majority of the women were aware of the existence of injectable, pills and implanted contraception. Although some of the women knew about the intrauterine contraceptive device (IUCD) and condoms, some related condom use with promiscuity rather than a method used in family planning. This can be partly explained by the paradoxical influence of the media in advocating condoms for prevention of sexually transmitted diseases and the cultural taboo to disclosure of

condom use (Alene, 2002; Hearst & Chen, 2004). Contradicting the findings in America, where women with mental illness were more likely to use permanent contraception such as sterilization, participants in this study were not aware of these options (Henshaw & Protti, 2010).

In summary, even though women of reproductive age with an SMI are vulnerable to unplanned pregnancy, are at risk for mental health relapse during child bearing, and could be exposed to psychological and economic burdens if an unplanned pregnancy occurs, none of the women with SMI in the present study had received any recommendations to use family planning services while receiving mental health care services.

5.1.4. Preferred family planning services among women with SMI

Existing mental health care in Ethiopia is centralized and largely restricted to urban settings. Most specialist mental health care services are confined to the capital city, Addis Ababa, and regional cities in the country. There are limited inpatient beds reserved in these sites, no specialist perinatal mental health services and almost non-existent psychosocial services. It could be argued that the service is virtually inaccessible for nearly more than 84% of the population who live in rural area (CSA, 2010). The women participating in our study were somewhat unusual in this respect because they were living in a rural area but had improved access to psychiatric nurse-led care as a benefit of participation in the Butajira SMI cohort study.

Integrating family planning services into specialist mental health services was generally preferred by the women in this study, in keeping with the first choice of women with SMI in HICs (Guedes et al., 2009). Participants emphasized the need for specialist knowledge, for example about interactions between their medications with contraceptives, the illness and the family planning approaches. They also felt more comfortable communicating with mental health professionals, with whom they had built up a relationship over a long period of time. They emphasized the need for clear communication in a way that they would be able to understand and thought that experts were better equipped for this.

The women in our study reported that there was a need for improved family planning advice and referral from mental health professionals. This result supports previous studies highlighting that recommendations by health professionals regarding family

planning recommendation need to be modified to address specifically the needs of women with SMI (Hauck et al., 2015; Henshaw & Protti, 2010).

Family planning services in Ethiopia are usually accessed through all levels of general health care services. However, few health professionals in Ethiopia deliver a comprehensive range of family planning methods suitable for women with SMI (FMOH, 2011). In part, this reflects the low priority which has been given to mental health care in the training of general health care providers. The plan to expand mental health care by integrating into primary care may provide an opportunity to better meet the family planning needs of women with SMI. However, there may need to be modifications for women with SMI.

Primary health care facilities are usually located within walking distance (under 10km) which may facilitate access to family planning care, but some women preferred the option of having family planning services at home due to concerns about privacy. In Ethiopia, community-based health extension workers have successfully expanded family planning services to the home, but women with SMI do not appear to have benefitted from this service expansion (CSA, 2014; Medhanyie et al., 2012). Indeed, participants in this study reported systematic exclusion. The practices of health extension workers, in terms of how they deliver family planning information for women with SMI, was felt to be deficient by the participants in this study (Bilal et al., 2011; Medhanyie et al., 2012). Another challenge is that family planning services in Ethiopia are focused on married women, but it is equally important to expand family planning services for unmarried women. This is particularly the case for women with SMI who may be vulnerable to sexual exploitation and coercion outside of marriage. While the sexual exploitation of women with SMI needs attention in its own right, the practical step of enabling access to contraception for single women with SMI may help women to protect themselves from unwanted pregnancy and the associated social sanctions.

Almost all of the participants agreed on the importance of awareness creation forums regarding family planning for women with SMI and the community at large. Participants stressed how this lack of awareness has put them at a disadvantage to access timely family planning care and has contributed towards stigma. Community-based health extension workers are well-placed to take on this activity as their main remit is in the area of health promotion and disease prevention.

5.2. Multi-dimensional Implications of the Research Findings

5.2.1. Implications of research findings for clinical practice

Overall, this qualitative study highlighted that, although women with SMI in Ethiopia felt that family planning was important, they had limited knowledge of family planning generally and a lack of understanding of the specific family planning needs relevant to having SMI. In addition, the women in the present study reported high levels of sexual trauma and victimization, further exacerbating their unmet need and highlighting the urgency of improving access to family planning services.

At the present time, family planning services in rural Ethiopia are provided by health extension workers who travel from house to house. The women in the present study identified a number of barriers to accessing family planning services in their present form. The initiative to improve family planning services for women with SMI is of cardinal importance as much as it is for other women. However, the lack of awareness among family members, the community and inadequate support from health professionals were identified as clear examples of barriers to utilize the existing package of family planning services. Continuous in-service training for primary health care workers on how to meet the specific family planning needs of women with SMI is important to fill the gap in family planning utilization among women with SMI. Despite the existing mental strategy to train primary health care professionals and health extension workers in basic mental health care, the practice is not adequate enough to provide comprehensive reproductive health care for women with SMI. The Federal Ministry of Health of Ethiopia is integrating the WHO mental health Gap Action Programme into primary health care services, but this does not specifically address the needs of perinatal women with SMI and mostly recommends specialist advice and referral.

In addition to addressing family planning services for women with SMI at the primary health care level, the women in the present study expressed that an integrated approach to family planning services in mental health care specifically was seen as the best way to encourage sustainable family planning service in women with SMI.

Therefore, mental health workers also have a role to play in improving access to family planning for women with SMI. If mental healthcare providers are going to provide family planning services for women with SMI, they will need to receive further training on family planning among this vulnerable group. Unfortunately, this is not a feasible option for women with an SMI living in rural areas with limited access to centralised

mental health care. For these women, the integration of family planning services into primary healthcare is the most appropriate option to address their needs.

Finally, women with SMI experience higher risk of sexual trauma and victimization when compared to women in the community. These women need to have a wider range of support from care providers and family members. In addition to efforts to tackle the root causes of sexual violence, mental health care professionals need to proactively screen women with SMI for exposure to sexual trauma and respond accordingly.

5.2.2. Implications for the National Health Policy

The findings of this qualitative study have implications for health policies related to family planning as well as mental health. The implications for health policies related to family planning will be described first. To begin with, in order to achieve the national plan to make all family planning methods accessible for all reproductive age women the current family planning services in Ethiopia must be expanded and reorganized to address the need of both married and unmarried women with SMI. Furthermore, the existing family planning services create various forms of barriers for uptake of contraceptives which need to be addressed. The barriers include the limited choice of family planning methods, unintentional concealing of full information about available family planning methods from providers by delivering the information in groups rather than individualized sessions for women with SMI. In addition, current awareness-raising approaches do not consider the needs of some women with SMI for additional time to understand and process the information. Moreover, inadequate or incorrect information based on personal biases from community members and the service users interfere with informed decision-making. Stigmatising attitudes that shun the rights of women with SMI to use family planning perpetuate inequalities for this vulnerable group. Lastly, health care professionals in family planning clinics have limited skilled in reproductive mental health. These limitations discourage the use of current family planning services by women with SMI.

Turning to implications for mental health policy, the evidence in this study shows that practicing mental health professionals mainly focus only on mental health care which cannot be complete without addressing the family planning and other reproductive needs of these women. This could be because of apparent lack of focus on this issue in the National Mental Health Strategy. The current primary care mental health service has challenges due to the brevity of training. Regular supervision of primary health

care providers by specialist mental health professionals and integration of family planning into mental health training would improve the service provided to meet the reproductive needs of women with SMI.

This study also underlines the importance of health workers discussing reproductive issues in general with women with SMI, as they are a vulnerable group for gender-based violence and adverse reproductive outcomes. The frequent negative physical and psychological consequences of sexual and reproductive health include the risk of unplanned pregnancy, complications of unsafe abortions and other sexual and reproductive health challenges. In addition to this, woman with SMI are less able to negotiate for safer sex practices due to their mental illness and fear of violence, including difficulties in disclosing their adverse experience to get timely help.

There is a pressing need for mental health advocacy to improve the community's awareness of mental health and to reduce stigma and discrimination against women with SMI who wish to utilize family planning services. Stigma affects women with SMI more than men with SMI, both in the health care system and in the community. Having a SMI limits women's active utilization of reproductive health care services because they are not perceived as credible persons who deserve the choice to utilize family planning services. These myths about the reproductive health rights of women with SMI exacerbate stigma in the community. The common negative attitudes and myths of stigma about mental illness continue to preserve the belief that women with mental illnesses are incapable of making decisions regarding their reproductive rights. Anti-stigma advocacy and education about mental health is needed for health care professionals at all levels of the care system and amongst the public to improve the utilisation of reproductive health and family planning services in women with SMI.

Finally, there is a need to design effective education and information provision methods to improve knowledge and utilization of family planning methods for women with SMI. Educating women with SMI about family planning is a necessary step in equipping them to make informed decisions about methods of contraceptive and other related issues.

5.2.3. Implications for future research

This study was one of the first of its kind to be conducted in Ethiopia among reproductive age women with SMI. In addition to answering the specific researchquestions, the qualitative findings identified other areas that could benefit from further investigation. There is a need for evaluation of the impact of the scale-up of primary care-based mental health care on uptake of family planning by women with SMI. Development of service models for family planning in both mental health and general health care settings need to be piloted and evaluated to ensure that they achieve their goal without increasing stigma against women with SMI. The impact of community awareness-raising campaigns also deserves scrutiny.

Even though not a focus of this research, it was apparent that intimate relationship problems, sexual trauma and economic factors are important unmet needs of women with SMI in this study. Further research is needed to design and evaluate appropriate interventions to address these needs.

5.3. Limitations

Several limitations affect the scope and breadth of the current study and/or the analysis of the findings. Purposive sampling was used in order to obtain in-depth information from women selected on the basis of differing family planning practices, but this means that participants may not have been representative of all women with SMI. This might also have been exacerbated by restricting inclusion to women who were not acutely sick and who were able to express themselves. Qualitative data relies heavily on self-report of the participants, with no external corroboration. An ethnographic approach might have helped to overcome this challenge but was not feasible.

Another potential limitation was that the sample was recruited from a cohort study in which the participants had relatively better access to mental health services and treatment. Going forward the inclusion of participants who are receiving treatment in PHC within rural Ethiopia could address this. At the time of the study, such services had not been established. Therefore, the results of the present study are not representative of all women with SMI in the country and the findings may be difficult to generalize to other contexts in Africa. However, the Butajira cohort was community-ascertained and not liable to the strong selection bias seen in facility-based studies in this context. The findings of extremely low levels of awareness and problems of

access, even in a relatively better-served population, indicate that the study is likely to be of value for service development in other areas of rural Ethiopia.

The second major limitation of the study has to do with language barriers resulting in issues of precise rendering of translations. The interview was conducted in Amharic transcribed by other professional and translated to English by psychiatry residents and young psychiatrists for whom English is second language. The result may be that some errors could have slipped into the subsequent English translation, which in turn may have possibly affected the interpretation of the results of the study, However, I have checked randomly the original Amharic transcription for consistency.

The third possible limitation of this study could be that its scope includes only women with SMI. The study excluded other groups of participants who are involved in the care of women with SMI. This includes health extension workers, primary health care professionals, psychiatric nurses, their caregivers and community representatives. Future research needs to look at the views and experiences of the other stakeholders such as health extension workers. Including these participants and having their perspectives may contribute to the development of a feasible and acceptable intervention.

5.4. Conclusion and recommendations

In conclusion, despite its limitations, this study is the first of its kind in Ethiopia to investigate family planning among women with SMI in a rural and low-income country setting. This study aims to explore the family planning experiences of women with SMI. The study has provided insights on the family planning experience of women with mental illness. It has also identified a range of factors influencing family planning service utilization in these groups of women. One of the most important findings of this study is that the current experiences of women with SMI do not match up with their own preferences in relation to the venues, agents and providers of the family planning service. Their experience was highly influenced by the attitudes of the women themselves, the community and some health professionals towards women with SMI regarding their relationships and sexual life. These attitudes are likely to hinder open discussion about family planning needs and uptake of family planning services by these women.

Although women with SMI in this study were positive about the potential benefits of family planning, barriers to using the existing family planning service were prominent.

These included: inadequate awareness, negative attitudes of the family, the community and the health care professional towards family planning. Therefore, mental health professionals should be involved in family planning for women with SMI where appropriate. In order to bring about improvement in family planning service utilization, there is a need to work on improving the awareness and attitude of women with SMI, the health care providers and the community. This can be achieved by training of family planning service providers, health extension workers and mental health professional on the unique needs of these women. Giving family planning services in the woman's' home or mental health clinics can also help to tackle the stigma towards service utilization.

Policy makers and implementers should attend to these unheard voices in the interest of effective family planning and the creation of healthy citizens.

Based on our finding from this study the following recommendations show that there are needs to:

1. Increase the knowledge of women with SMI, the general community, and healthcare professionals about the particularities of family planning in women with SMI.
2. Improve the awareness of the women with SMI and the general community to decrease stigma towards use of family planning services by women with SMI.
3. Expand support to women with SMI to meet both their health and social needs, e.g., to reduce sexual exploitation, help to overcome their social exclusion and economic marginalization
4. Facilitate more accessible and convenient services for women with an SMI in the same facility where they receive mental health care or at the primary healthcare level through community health workers.
5. Explore the existing family planning service, the extent of family planning utilization and factors which determine family planning utilization in women with SMI
6. Overcome barriers to accessing the existing family planning services for women with a SMI, e.g. through collaboration and communication between mental health care professionals and other health care providers. This is necessary to address both mental health and family planning needs of these women such as the impact of timing of pregnancy and the effect of psychotropic medication.

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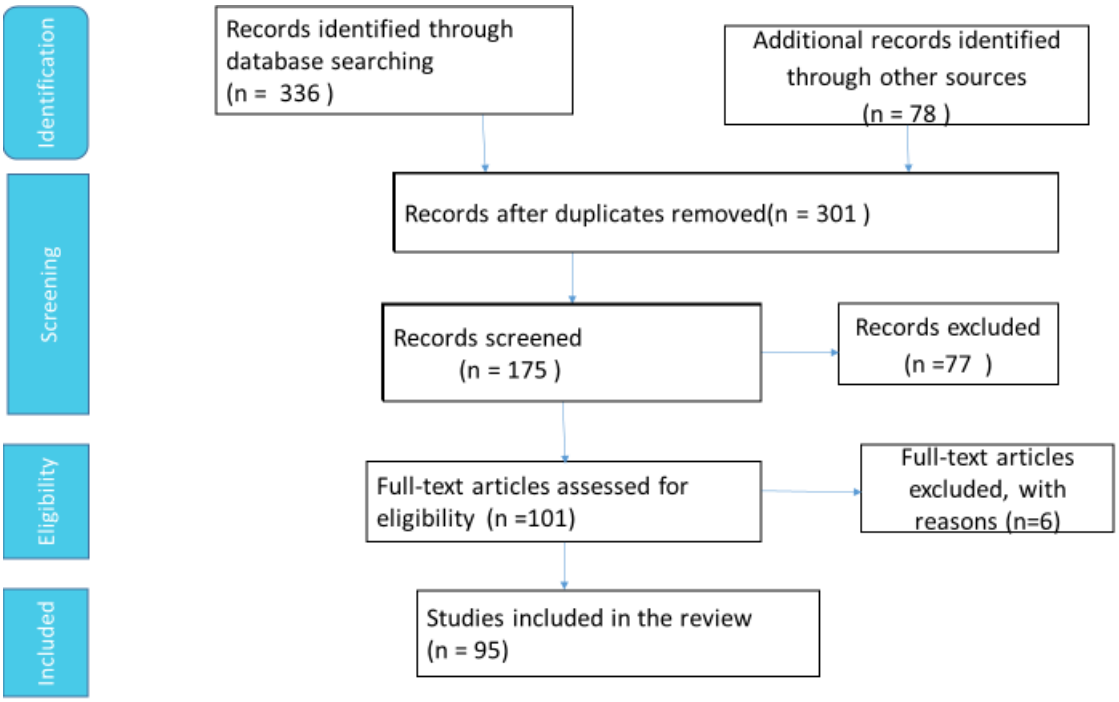
Appendices

Appendix A: - PRISMA 2009 Flow Diagram



Appendix B: - Participant information sheet for initial quantitative survey.

TITLE: - Family Planning for Women with Severe Mental Illness (SMI) living in predominantly rural of Ethiopia: A qualitative study.

Principal Investigator:-Dr Tigist Zerihun Kebede

Address: Amanuel Specialized Hospital, Addis Ababa, Ethiopia

Cell: - + 2510928677767

Funding organization: National Institute of Mental Health, African Focus on Intervention Research for Mental Health (AFFIRM), University of Cape Town, Department of Psychiatry and Mental Health, South Africa

In this is a mental health research study we will be collecting data for the purpose of research. This form explains why we are planning to do this study, your role in the study, the benefits and risks of getting involved in this study, compensations and confidentiality of the information you give to the data collectors. The information that is collected from you in this interview, will be used as part of the research.

a) Purpose- The purpose of this study is to explore the family planning experiences of women living with severe mental illness who reside in a rural area of Ethiopia. You may also be asked to participate in a longer interview conducted by the principal investigator (Dr Tigist Zerihun).

b) Duration- The interview will take about 20 minutes.

c) Procedures to be carried out- Brief introduction given by the data collector and the consenting women will be asked questions, their answer written on the paper by the data collector There will not be any invasive procedures.

d) Risks associated with the study- Apart from the time you spend with us we do not see any risk to you of participating in this study

e) Benefits of the study- We hope that the study will contribute to the improvement of family planning services for women with severe mental illness in Ethiopia.

f) Compensations- There is no compensation for participating in this short interview.

g) Confidentiality of your information- The information you give us during this study will be confidential. Once the data is entered into a computer, it will be given a number so that nobody except the study researchers will be able to identify that it belongs to you. Personal information that could lead to your identification will never be disclosed, either in oral or written form.

h) Termination of the study- You will only be recruited based on your willingness to participate and without any obligation to participate in the study. Once you get involved in the study, you also have the right to withdraw your participation before completing the study.

I would also like to inform you that this study is approved by the ethical committees of the University of Cape Town and scientific committee of Amanuel Mental Specialized Hospital in Addis Ababa.

The ethics committees address / contact details are;

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

Scientific Committee of Amanuel Mental Specialized Hospital, Addis Ababa Ethiopia

Contact person Dr. Lulu Bekana Tel. +251112137971

Appendix C: -Consent form for initial quantitative survey.

You have been asked to participate in the study with the title “family planning for women with severe mental illness”. Participating in this study will only depend on your decision to do so and you have the right to withhold information, refuse participation or to drop out of the study at any time that you want to do so without any need to explain to anyone. Withdrawing from the study will have no adverse consequences for you. All the information you give during the study will be kept confidential.

You have the right to ask questions and request clarification at any time. In case you have doubts or questions, you can use the above address to access the principal investigator. After giving this information you may also be asked to participate in another interview that will be conducted by the Principal Investigator, Dr. Tigist Zerihun.

Finally, I would like to ask you to confirm your agreement by signing (putting finger print) your name if you agree.

Declaration of participant

By signing below, I, _____, agree to take part in a research study on “Family planning for women with severe mental disorder (SMD) in rural Ethiopia”.

I declare that:

☐ I have read (or the data collector read) this information and consent form and it is written in a language with which I am fluent and comfortable.

☐ I have had a chance to ask questions and all my questions have been adequately answered.

☐ I understand that taking part in this study is voluntary and I have not been rushed to take part.

☐ I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

☐ I may be asked to leave the study before it has finished. This may occur if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan as agreed to.

☐ I was told that I may be asked to be participate in the second interview conducted by the PI

☐ I understand that the information I give during this study will be confidential

Appendix D: - Questionnaire for quantitative interview for women with SMI

Please answer the questions below

Key Demographics

1. Age ----------
2. Marital status ----------
3. Employment ----------
4. Educational level ----------
5. Place of residence 1) rural 2) urban
6. Diagnosis ----------
7. Are you taking medication? 1) yes 2) No
8. If yes, when did you start taking medication? ----------
9. List current medication and dose:
10. Do you have children? 1) yes 2) No
11. If yes, how many children do you have? ----------
12. Are you pregnant currently? 1 = Yes 2 = No [If no, skip to question 14]
13. At the time, you became pregnant, where you using contraception?

1) Not using contraception 2) Tablets 3) Injection 4) Natural (timing) 5) Condoms

14. Is there any method you prefer from the above methods and Why?
15. Do you want to be pregnant now? 1=Yes 2=No
16. Do you want to have more children? 1=Yes 2=No
17. If 1, do you know of any ways to prevent pregnancy? 1=yes 2=No
18. Are you using any family planning methods currently?

1) Not using contraception 2) Tablets 3) Injection 4) Natural (timing) 5) Condoms

6) sterilized (woman) 7) sterilized (partner) 8) other

18. If not using family planning methods, what is the reason?

1) I want to have another child 2) My husband wants another child

3) My husband does not allow me 4) My religion does not permit me

5) For health reasons (either can't tolerate side effects or has medical contraindication)

6) FP services not available 7) I don't know about methods of preventing pregnancy

8) Leave it to nature 9) Don't live with husband

10) Other, specify:

19. If using family planning methods, which do you prefer, and why?
20. Do you want to have more children in the future? 1= Yes 2 =No

Appendix E: - Interview guide for women with severe mental illness

The main aim of the study is to explore the experiences of women living with severe mental illness of family planning interventions in Ethiopia. During this interview, I would like to get your views on the ways in which you are getting information regarding family planning, as well as your attitudes and experience related to family planning. I value each one of your thoughts and opinions. Please remember that there are no right or wrong answers. Please feel free to discuss what you think. If there are issues that you really do not want to discuss you are free to not do so. Everything that is discussed in the interview is considered confidential this interview should last for about 45 minutes to 1 hour. I would like to record the interviews with your permission, to write down every word from the recordings and then try to understand what you and the other participants have said. These responses will be presented in reports. No identifying information such as names will be included in the reports.

Thank you for helping me with this study.

Participant No/Pseudonym ---------- Date of Interview ----------
----- Interview Start time ----------. Interview end time ----------

. Tell me a little bit more about your living conditions?

----------Notes: Prompt

a) With whom you are living?

b) Who supports you? Who do you support?

2. Please tell me what you know about family planning?

Notes: - ----------
Prompt: -

What are the different methods that you know about? Have you used any of these in the past?

[If relevant] What is the method of choice for you and why do you prefer that method?

3. Please tell me about your views around having children

Notes: - ---------- Prompt: -

a) What are your views about you having children as mentally ill women?

b) When should women with severe mental illness have children?

c) What are the ideal conditions to have children being mentally ill? (Disease condition and treatment)

d) See the comments what do others in your family think? Why do you think they think that way?

e) Are there any issues you think about regarding having children and living with a mental illness?

f) What are your views on How other people (E.g. health workers, relatives, communities) feel about mentally ill women bearing children having?

g) What do you think about the views of the community/t peoples?

4. What do you know about current services regarding family planning in the health facility?

Notes: - ----------

Prompts: -

a) What would you hope the Family planning service in the health facility would provide for you*?*

b) What have you actually experienced *regarding family planning service in the health facility?*

c) How important do you think it is to have an intervention to plan pregnancy?

d) What extra support of information you should be given about medication, risk of unplanned pregnancy?

e) Tell me good things about the service you received?

f) Tell me any problems you face during service utilization?

g) Do you have any ideas for how these difficulties might be overcome?

4. Now I would like to ask you to talk about your experiences with family planning services at the health facility, what do you think about it?

----------Notes: - ---------

---------- Prompts: -

a) Drawing on your own experience, can you give me an example of a time when you were forced with health professional or other peoples to use the family planning methods b) What would be positive about having family planning Service?

c) What would be negative about havening family panning service? (Attitude)

d) What will be the barriers to have the service you mentioned?

e) Do health providers give you information about family planning or made referral?

Were the referrals taken up do you get the service as you want?

f) In general, do you think women who have severe mental illness need extra help to access family planning? Why is that? What sort of help?

g) Can you tell me about any difficulties you face getting the family planning service?

Any other difficulties?

h) Can you tell me your ideas for how those problems could be overcome? What would help you to be able to access family planning?

i) How would you describe the perfect environment for you to use family planning methods?

5. In what ways do you think that the current family planning service could be improved? ----------
Notes:

Prompts: -

a) What kinds of things/ interventions approaches are in currently in place?

b) What would be the best ways to get Family planning service for you?

---

c) Where is the best place to get the family planning service? In the facility? In your home?

d) What about providing information about family planning for the women visiting this service?

e) What kind of help do you need from health workers or health system so that you can get the family planning service that you need?

7) Do you have anything else to share?

----------Notes:

Summary of the Whole interview

Appendix F: - Capacity to consent

Date (Ethiopian)		[ ][ ]/[ ][ ]/[ ]
Patient ID		[ ][ ][ ]
In relation to participating in the qualitative study,		
Is the participant able to express a choice?		Yes ☐ No ☐
Does the participant make reasonable decisions?		Yes ☐ No ☐
Does the participant make decisions based on rational reasons?		Yes ☐ No ☐
Does the participant understand the risks and benefits of participation?		Yes ☐ No ☐
Does the participant fully understand all relevant aspects of the decision and give a truly voluntary and informed consent?		Yes ☐ No ☐
Interviewer comments (optional)		

Appendix G: -Participant consent form for in-depth interview

By signing below, I……., agree to take part in a research study on "Family planning for women with severe mental disorder (SMD) in rural Ethiopia"

I declare that:

☐ I have read (or the researcher has read out) this information and consent form and it is written in a language with which I am fluent and comfortable.

☐ I have had a chance to ask questions and all my questions have been adequately answered.

☐ I understand that taking part in this study is voluntary and I have not been rushed to take part.

☐ I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

☐ I may be asked to leave the study before it has finished. This may occur if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan as agreed to.

☐ I was asked permission to audio-record and transcribe the interviews

☐ I understand that the information I give during this study will be confidential.

Signed at_____on _____2014/2006EC. Signature of participant_/Finger print ----------

Signature of witness ----------

Declaration by investigator

I, Dr. Tigist Zerihun Kebede, declare that:

- I explained the information in this document to _____.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Sign Signed at _____on ----------2014/2006EC. Signature of investigator ----------

Signature of witness ----------

Appendix H: -Participant information sheet for in-depth interview

You are being invited to take part in a study project.

I am going to give you detailed information about this project. Please ask any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely depend on your free will and you are free to withdraw from the study at any time – even in the middle of the interview. This will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part at the beginning. This study has been approved by the Health Research Ethics Committee at the University of Cape Town in South Africa and the Scientific Committee Amanuel Mental Specialized Hospital, Addis Ababa

1. What is this research study all about?

The aim of this study is to understand more about the family planning experiences of women with severe mental illness who are participating in the Butajira cohort study project. The study will be done in the Butajira district, Ethiopia. I (Dr. Tigist Zerihun Kebede) am the head of the research. I will conduct an interview with each person who agrees to take part in the research. I would like to record the interviews with your permission, to write down every word from the recordings and then try to understand what you and the other participants have said. With your permission, I would like to audio record the interview so that I do not miss any important information. After the interview, has been put into a written format and the analysis has been completed, the tape recording will be destroyed. During the interview, you will be asked about your experience regarding family planning services.

2. Why have you been invited to participate?

You have been invited to participate, because you were part of, or are currently still part of, the ongoing Butajira study on mental illness.

3. What expected from you?

As a participant, you are requested to share as openly and freely as you possibly can about your experiences according to the questions that I will ask you on family planning, child bearing and mental illness.

4. Will you benefit from taking part in this research?

As a participant, you stand to benefit a clearer understanding of your own experiences in the current service. Understanding the existing service for women living with severe mental illness will help to improve services in the future.

5. Are there in risks involved in your taking part in this research?

It is possible that you might experience feelings of discomfort when talking about your experiences. However, I will ensure that a qualified person in mental health person is available to talk to you about these feelings, should you wish to do so.

6. If you do not agree to take part, what alternatives do you have?

If you do not agree to take part, it will have no effect on the treatment that you receive in the Butajira project.

7. Who will have access to your medical records?

I do not need any access to your medical records to conduct this research.

8. Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport costs will be covered. There will be no costs involved for you, if you do take part.

9. Will the information you give be confidential?

The information you give during this study will be confidential. Once the information in the audio recording has been written down, word for word, it will be coded and becomes unidentifiable/ anonymous. The audio recording will be locked in the office cabinet and destroyed after the data analysis is completed. Personal information that could lead to your identification will never be disclosed either in oral or written form.

10. Is there anything else that you should know or do?

If you have any concerns or complaints that have not been adequately addressed by the researcher, you can contact the scientific committee of Amanuel Mental Specialized Hospital on +251112137971. You will receive a copy of this information sheet and consent form for your own records.

Appendix I: - Institutional Review Board letters of approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: shurella.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

04 September 2014

HREC REF: 265/2014

Dr K Sorsdahl
Psychiatry & Mental Health
J-Block, GSH

Dear Dr Sorsdahl

PROJECT TITLE: FAMILY PLANNING FOR WOMEN WITH SEVERE MENTAL ILLNESS (SMI) LIVING IN PREDOMINANTLY RURAL ETHIOPIA: A QUALITATIVE STUDY (Masters Candidate - Dr T Kebede)

Thank you for your letter to the Faculty of Health Sciences Human Research Ethics Committee dated 28 August 2014.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th September 2015.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

We acknowledge that the student, Dr Tigist Zerihun Kebede will also be involved in this study.

Please quote the HREC reference no in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 265/2014

This serves to confirm that the University of Cape Town Human Research Ethics Committee comp to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135 and FDA Code Federal Regulation Part 50, 56 and 312.

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

-4 SEP 2015

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	20.9.2016
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	5/9/2015

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	03/09/2015		
HREC REF Number	265/2014	Current Ethics Approval was granted until	30/9/2015
Protocol title	FAMILY PLANNING FOR WOMEN WITH SEVERE MENTAL ILLNESS (SMI) LIVING IN A PREDOMINANTLY RURAL AREA OF ETHIOPIA: A QUALITATIVE STUDY		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes ✓ No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Katherine Sorsdahl (student: Tigist Zerihun Kebede)		
Department / Office Internal Mail Address	Alan J Flisher Centre for Public Mental Health 46 Sawkins Road Rondebosch 7700		

1.1 Does this protocol receive US Federal funding?	☐ Yes	✓ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	✓ No
1.3 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget	☐ Yes	✓ No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Ethical clearance letter from local Ethics review board

Minutes of the Ethical Review Committee

Date: July 15 ,2014

Time: 9:00

Dr. Lulu Bekana
Psychiatrist

Members present

1. Dr. Lulu Bekanna Chairperson
2. Dr. Dereje Asefa Member
3. Ato Zageye Yohaness Member

Agenda:

Evaluation and deciding whether the project proposal "FAMILY PLANNING FOR WOMEN WITH SEVERE MENTAL ILLNESS (SMI) LIVING IN A PREDOMINATLY RURAL AREA OF ETHIOPIA A QUALITATIVE STUDY) "

Presented by: Dr TIGIST ZEREHUN KEBEDE

After deliberations, the Ethical Review Committee accepted the proposal to be ethical sound, and could be undertaken in the hospital.

ከአእምሮ ጤና ልማትም ሆነ ደህንነት የለም! There is no development or health without mental health!

የኢትዮጵያ ፌደራላዊ ዲሞክራሲያዊ ሪፐብሊክ
በጤና ጥበቃ ሚኒስቴር
የአማኑኤል አእምሮ ስፔሻላይዝድ ሆስፒታል
Federal Democratic Republic of Ethiopia
Ministry of Health
Amanuel Mental Specialized Hospital

ቁጥር Ref. No AM/W49/4/33
ቀን Date July 24/2014

To: Dr TIGIST ZAREHUN KEBEDE

The Ethical Review committee of the Amanuel Mental Specialized Hospital has gone through your project proposal "**FAMILY PLANNING FOR WOMEN WITH SEVERE MENTAL ILLNESS (SMI) LIVING IN A PREDOMINATLY RURAL AREA OF ETHIOPIA A QUALITATIVE STUDY)** ". The committee found nothing unethical in the methodology of acquiring data or in the overall content of the project proposal. It also believes that the results of this study will contribute in filling the knowledge gap in understanding the reasons for "**FAMILY PLANNING FOR WOMEN WITH SEVERE MENTAL ILLNESS (SMI) LIVING IN A PREDOMINATLY RURAL AREA OF ETHIOPIA A QUALITATIVE STUDY)** " and the meaning attached to it. The committee informs you that you are allowed to continue your research in the hospital and the clinical departments are here by informed for giving you the necessary support required.

With Regards

Dr. Fufu Bekana
Psychiatrist

Research and Training Directo

CC//

- CEO
- Research and Training Directorate
- Medical Director Office

Amanuel Mental Specialized Hospital

Tel. 011-213-26-77/011-275-76-98 Fax - 251-11-275-77-23
011-275-76-99
P.O.Box 1971
Addis Ababa Ethiopia

ኅብረተሰብ ጠና ልማትም ሆነ ደህንት የለም! There is no development or health without mental health!

በኢትዮጵያ ፌደራላዊ ዲሞክራሲያዊ ሪፐብሊክ
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Federal Democratic Republic of Ethiopia
Ministry of Health
Amanuel Mental Specialized Hospital

ቁጥር Ref. No. Am/1461514/40
ቀን Date Aug 8/2014

Research Ethics Committee

Amanuel Specialized Mental Hospital

Addis Ababa, Ethiopia

Professor Marc Blockman

Chairperson, Faculty of Health Sciences Human research Ethics Committee

University of Cape Town, South Africa

Email: marc.blockman@uct.ac.za

8th August 7, 2014

Dear Professor Blockman

Re: HREC REF 265/2014

Project title: " Family planning for women with severe mental illness living in predominantly rural Ethiopia a qualitative study" (Mphil Dr. Tigist Zerihun)

I am writing on the behalf of **Amanuel Specialized Mental Hospital Ethics Committee** that we are happy to be included on the information and consent form for the study and we will absolutely communicate you /UCR HREC / in the event that any issues arise with the study using the above email.

With regard

ሰብ ቢቃና
Psychiatrist

Chairperson Research Ethics Committee

CC

Research and Training Department
Record office

Tel. 011-213-26-77/011-275-76-98 Fax - 251-11-275-77-23 P.O.Box 1971
011-275-76-99 Addis Ababa Ethiopia